

Using experiential learning to facilitate pharmacy
students' understanding of patients' medication practice
in chronic illness

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ABSTRACT

This study originates from experiences which led me to question the way pharmacists are equipped to advise and support the medicine-taking practice of patients using chronic medication.

The study offers a critical theoretical consideration of underlying perspectives informing pharmacy education. I propose following a critical realist ontological perspective, a social realist understanding of social structure and human agency, and a sociocultural epistemology. Based on these perspectives, I consider a sociological critique of ‘health’, ‘disease’, ‘illness’ and ‘sickness’ perspectives on medicine-taking, and of pharmacy as a profession. I then propose an experiential learning approach, with an emphasis on developing reflexivity through affective learning. I follow this with an illustrative case study.

Following a critical discourse analysis of student texts from the case study, I conclude that there is evidence that experiential learning may prove useful in developing pharmacy students’ reflexive competency to support the provision of pharmaceutical care to patients using chronic medications.

DEDICATION

This thesis is dedicated to six people:

- The young man, unknown to me, whose donated heart I received in a transplant;
- His parents, equally unknown to me, who in their grief, made the courageous and gracious decision to give the ‘gift of life’ to strangers by granting their permission for their son’s organs to be donated;
- My father who died of heart failure and for whom there was no transplant option;
- My sister who served as a theatre sister on the first transplant, and who died of heart failure thirty years later, making choices for quality and not quantity of life;
- And to Christopher Tompkins whose courage, creativity, wisdom and spiritual strength was neither contained by convention, nor diminished by disease.

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Kevin Williams

Grahamstown, South Africa

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Terms & Acronyms used in this thesis

Term	Usage
Biomedicine	Although the term has come to describe a generic understanding of Western medicine, it originated in the 1960's project of describing and understanding pathology in terms of biological mechanisms. While there is some rejection of this reduction, there is a general sense in which such a model continues to underpin Western allopathic medicine (Keating & Cambrosio 2004).
Chronic illness	Chronic illness (-disease, -medical condition, -disorder) is characterised by persistent resistance to treatment resulting in condition-endurance, frequently incurable, sometimes 'silent' (displays no perceptible symptoms), signs (biological findings) do not always correlate with symptoms (patients' experience), is frequently insidious, and is often marked by increasing levels of discomfort or pain with more or less severe life-style implications (Assal 1999; Watt 2000).
Competency	'Competency' is used in a way compatible with the understanding held by the South African Qualifications Authority (SAQA), namely as ' <i>Applied competence</i> ... [that is]... the overarching term for three interconnected kinds of competence. <i>Practical competence</i> is the demonstrated ability, in an authentic context, to consider a range of possibilities for action, make considered decisions about which possibility to follow, and to perform the chosen action. It is grounded in <i>foundational competence</i> where the learner demonstrates an understanding of the knowledge and thinking that underpins the action taken: and integrated through <i>reflexive competence</i> in which the learner demonstrates ability to integrate or connect performances and decision-making with understanding and with an ability to adapt to change and unforeseen circumstances and to explain the reasons behind these adaptations' (SAQA 2000:10).
Dispensing	'the interpretation and evaluation of a prescription, the selection, manipulation or compounding of the medicine, the labelling and supply of the medicine in an appropriate container according to the Medicines Act and the provision of information and instructions by a pharmacist to ensure the safe and effective use of medicine by the patient...' (Pharmacy Act 2000 quoted in PCSA 2004:32).
Drug	'any substance or mixture of substances used for or purporting to be suitable for use or manufactured or sold for use in the diagnosis, treatment, mitigation, modification or prevention of disease, abnormal physical or mental state or the symptoms thereof in man; or restoring, correcting or modifying any somatic or psychic or organic function in man, and includes any veterinary medicine' <i>Medicine and Related Substances Control Act</i> (101/1965).
Drug related needs	Problems relating to a patient's health care which in some way involve the use of drugs.
Drug related problems	Problems patients are undergoing, or may potentially undergo, that are in some way related to the use of, or failure to use, drugs.

Term	Usage
Emergent / emergence	<i>Emergence</i> was first used – somewhat diffidently – with respect to social structure by Mandelbaum in 1973. In critical / social realism emergence simply refers to non-observable entities, ‘a property which comes into being through social combination... [emergence exists] by virtue of inter-relations, although not all relations give rise to them’ (Archer 1995:51).
Ideology	‘A system of shared beliefs that legitimize particular behavioral [sic] norms and values at the same time that they claim and appear to be based in empirical truths. Ideologies help to transform power (potential influence) into authority (legitimate control)’ (Trostle 1988:1300).
Intransitive	Critical Realist (CR) philosophers refer to reality as being structured and stratified into three domains, the real, the actual and the empirical (moving from deepest to most accessible). The real belongs to what CR terms the <i>intransitive</i> domain. While Bhaskar does not anywhere explicitly define this term, he uses it in ways which link to linguistic usage of the term, and to the linguistic and philosophical usage of the second dimension, the <i>transitive</i> . I understand <i>Intransitive</i> to suggest that: (1) the relationship between the third domain of reality (Empirical) cannot be reduced to the first (Real), but the Empirical does relate to the Real through the Actual (the second domain); (2) a relatively unchanging and enduring quality; (3), that, as in linguistics usage denoting a verb that does not require a direct object, so the Real does not require a deeper referent. (Linguistic definitions from <i>Collins Dictionary of the English Language</i> , 1979) (See also ‘Transitive’).
Medicalization	From a critical sociological perspective has emerged the challenge to what is termed <i>medicalization</i> of society, understood as ‘the desocialization and reification of disease and illness and the explanation of social problems in biomedical terms’ (Filc 2004: 1277).
Naturalism	‘naturalism’ and ‘naturalistic’ are unfortunately words for which a variety of conflicting meanings are available in philosophical debate. Phillips (1999) provides an excellent (if somewhat ideologically driven) overview of these meanings. In this study ‘naturalism’ is used as Bhaskar (1979; 2002) interprets it: ‘... <i>naturalism holds that it is possible to give an account of science under which the proper and more or less specific methods of both the natural and social sciences can fall...it does not deny that there are significant differences in these methods, grounded in real differences in their subject matters and in their relationships in which their sciences stand to them. In particular...ontological, epistemological and relational considerations all place limits on the possibility of naturalism (or rather the form it must take...</i> ’ (Bhaskar 1979:3). This understanding is qualified by a rejection of both reductionism and scientism, and their underlying positivism (Bhaskar 1979).
Patient	As a person who lives with a high-risk chronic medical condition, I am fully aware of the contentious nature of the use of this term to describe people living with chronic illness, in relation to a healthcare professional. I am also aware of the growing rejection of the term in critical medical sociology and health psychology. For the sake of accessibility and readability, however, I have chosen to remain with the term in general usage rather than any of the as yet unsettled alternatives such as ‘people living with chronic illness’.

Term	Usage
Pharmacokinetics	‘[D]eals with the changes of drug concentration in the drug product and changes of concentration of a drug and / or its metabolite(s) in the human...body following administration, i.e., the changes of drug concentration in the different body fluids and tissues in the dynamic system of liberation, absorption, distribution, body storage, binding, metabolism, and excretion’ (Ritschel 1992:13).
Pharmacy Practice	‘those activities of pharmacists that most closely and directly impact on or interact with the final consumer of medicines, be they patients or users’ (Wingfield, Bissell & Anderson 2004:2384). In this thesis the term is thus used to describe the direct interaction(s) between pharmacy professionals and patients and / or their care-givers. The usage specifically includes retail, community and hospital pharmacy (See also ‘The act of medicine / pharmacy’).
Social Structure	While traditionally in sociology ‘structure’ has referred to ‘any recurring patterns of social behaviour’ (Marshall, <i>Dictionary of Sociology</i>), social realism’s rejection of empiricism suggests a significantly different understanding. <i>Social structure</i> is understood as referring to ‘a set of internally related elements whose causal powers, when combined, are emergent from those of their constituents’ (Sayer 2000:14). Structure is therefore ‘ <i>quintessentially relational</i> but none the less real because of its emergent properties which effect agents who act within it and thus cannot be reduced to their activities’ (Archer 1995:106 Italics in original).
The act of medicine / pharmacy	The moment where medical / pharmaceutical science meet human experience in the interaction between healthcare practitioner and (a) patient (See also ‘Pharmacy Practice’).
Transcendental argument	Arguments for the understanding of something which flow from questions such as: What must be the case for α to be possible? (Bhaskar 1978; 1979; Benton & Craib 2001).
Transitive	As with <i>Intransitive</i> , CR uses this term to refer to a dimension of reality, specifically to the two accessible domains of reality, the Actual and the Empirical. In essence although an issue of ontology, the <i>transitive</i> dimension relates to that which is known, but being geo-historical, it can and does change as with any other social construction. In linguistics <i>transitive</i> adjectives require implicit or explicit reference to noun phrases and in philosophy (logic) a <i>transitive</i> object bears relationships downwards through a second object to a first object, thus ultimately depending on the first. So on CR’s perspective, the <i>transitive</i> depends, emerges from, the <i>Intransitive</i> (Linguistic definitions from <i>Collins Dictionary of the English Language</i> , 1979) (See also ‘Intransitive’).

Acronym	Referent
ADR	Adverse drug reaction(s)
AIDS	Acquired Immune Deficiency Syndrome
BPSM	Biopsychosocial Model
BPSP	(Revised) Biopsychosocial Practice
CDA	Critical Discourse Analysis (Fairclough)
CEP	Community Experience Project
CFS	Chronic Fatigue Syndrome
DRP	Drug related problem
FIP	International Pharmaceutical Federation

Acronym	Referent
GIT	Gastro-intestinal
HCP	Healthcare professional(s)
HIV	Human Immuno-Virus
IBS	Irritable Bowel Syndrome
IPCSA	Interim Pharmaceutical Council of South Africa
NSAIDS	Non-steroidal Anti-inflammatory Drugs
PAP	Pharmacy Administration and Practice
PCP	Patient Care Plan
RA	Rheumatoid Arthritis
SAPC	South African Pharmacy Council
SAQA	South African Qualifications Authority
SARS	Severe Acute Respiratory Syndrome
WHO	World Health Organisation

Chapter 1 : Introduction

The research imperative to find universal (i.e. generalizable) interventions or drugs that work in preplanned, standardized ways that sell is overwhelming. “Just give me the evidence” means “Give me the numbers,” which means “Demonstrate a good profit line,” which means “Assure my endangered, privileged status.” Welcome to the clinical research space (Miller & Crabtree, 2000: 607 – 8).

The core clinical skills of listening, questioning, delineating, marshalling, explaining, and interpreting may provide a way of mediating between the very different worlds of patients and health professionals. Whether these tasks are performed well or badly is likely to have as much influence on the outcome of the illness from the patient's point of view as the more scientific and technical aspects of diagnosis or treatment (Greenhalgh & Hurwitz 1999:50).

1.1 Introduction

This study is concerned with the ‘very different worlds of patients and health professionals’ (Greenhalgh & Hurwitz 1999:50). Within this very broad (and well documented) area, my primary concern is to suggest an approach to enabling pharmacy students to gain insight into, and appreciation of the agency behind, the *medication practice* (Conrad 1985; 5.1.4.1 below) of people living with chronic illness. The primary purpose of the study is the theoretical development of an approach to teaching and learning within a pharmacy course. To give some shape to this theoretical contribution, the study includes an illustrative case study of a course developed on the basis of the proposed approach and undertaken as a final-year elective in a four-year Bachelor of Pharmacy degree at Rhodes University during 2004.

1.2 Origins of the study: personal and professional

The study originated through the juxtaposition of my professional experience as a higher education curriculum consultant, and my personal experience as someone who has been ‘cured’ of a ‘disease’ and yet is chronically ill with the cure. The focus on pharmacy was sharpened by my work with the Pharmacy Faculty at the university. These experiences led to the development of a Bachelor of Pharmacy fourth year Elective designed according to the theoretical principles proposed in the study. The course offered to pharmacy students in 2004 serves as the illustrative case study.

Inserting a personal account in an academic document is a risk. It is, I would argue, important in this case as it serves to alert readers to both explicit and possibly implicit agendas which are present within the study. My account serves to uncover the circumstances in which the research question was posed.

1.2.1 Personal illness

I underwent a heart transplant in January 2000. The circumstances that led to the transplant reflect the context of risk (Beck 2000) in which healthcare practice occurs, and the socially constructed nature of medical diagnosis. The precipitating condition which I experienced was persistently misdiagnosed (as asthma, bronchitis and then pneumonia) despite protestations of ‘scientific evidence’ which were used to refute my (lay) opinions that I was suffering from a heart-related ailment from which both my father and sister had died the previous year. My subsequent descent into heart failure resulted in such severe damage that a transplant was recommended as the only alternative to my death within six months.

In the process of the diagnosis of heart failure, the specialist physician highlighted the problems involved in diagnosis by pointing to the numerous x-ray images that had been taken to substantiate the ultimately unsustainable diagnosis of pneumonia. In each case while there was very slight indication of fluid in my lungs, the small-town general practitioner (GP) had been so focussed on his diagnosis that he had failed to allow his gaze to drop to the lower right-hand section of each x-ray (see Geisler 1994 and 2.2.1 below for reference to a study of medical expertise and the interpretation of x-rays). Had the GP lowered his gaze, he would have noticed a steadily increasing heart shadow indicative of an enlarged heart. There were other indicators he chose to either ignore or to fit with his diagnosis: increased heart rate (140 beats per minute at rest), bouts of severe breathlessness at night, my inability to walk up any incline - all of which he had attributed to ‘pneumonia’; my experience of palpitations, which he dismissed as ‘simply being aware of my heart because of my fear’; and my family history of heart failure as a result of myocarditis (which was dismissed as ‘co-incidence’).

What exacerbated my frustration at having my own experience dismissed as irrelevant to a diagnosis was the contrasting experience of medical care that I subsequently experienced from the transplant team. The team, consisting of cardiologists, cardiothoracic surgeons, a clinical pharmacist, two specialist nursing sisters, a clinical psychologist and a clinical social worker,

plus the usual range of paramedical professionals, assume that if a patient¹ experiences a problem it is the team's responsibility to work at understanding this problem in order to help the patient. Patients are included in every decision regarding their care, from treatment options to meals. If a patient is unwilling or unable to participate due to her/his condition, then family or caregivers are as involved as possible. At any point the patient or caregivers may call a halt to treatment, and their wishes are respected and the team offers what palliative care they can. While ultimately it is the team that makes the decision as to whether a prospective transplant recipient is placed on the waiting list, the final decision as to whether to put one's name on the list and whether to accept the heart, when and if such an opportunity arises is, left to the patient / caregivers. At no stage are the risks minimized, nor are the life-style consequences of accepting a transplant hidden. The team makes arrangements for prospective recipients to meet privately with previous recipients and their families to discuss the decision.

In my post-transplant experience the approach to care has remained the same. The pharmacist's role has become crucial in the post-transplant years because of the high-risk nature of the medication. The day before I left intensive care the pharmacist met with me to discuss and plan my initial medication practice. Unlike many hospital contexts, I was given responsibility for my medication from the first day in the ward (although nursing staff did 'remind' me). Had I been under the age of sixteen my caregivers would have been involved in this process. The role of the pharmacist became central in negotiating a medicine-taking regimen that remains reasonable within my normal post-hospital life, and the transplant surgeon has accepted the advice of the pharmacist in this respect. The pharmacist was also responsible for ensuring that I (and any recipient from age twelve and up) was able to identify my specific medications from a pile of assorted medicines dumped on the bed, name each item and explain its purpose (in general terms), side-effects and important interactions (dietary and medicinal). I was also required to explain missed-dosage and accidental over dosage procedures.²

Five years post-transplant I have a new understanding of what the relationship between myself and a healthcare practitioner can be. In many cases I know more about possible drug

¹ See 'Glossary' for my use of this word.

² So effective is this process, that on one occasion a seven year-old isiXhosa speaking child who lived some 1200km away from the centre, phoned the transplant coordinator one morning to say that her mother had left for work without giving her her medications. The young girl then listed (by name or description) the medicines in front of her and asked whether these were the correct ones to take.

interactions and therapeutic concerns related to my medicine regimen than the healthcare practitioners with whom I come into contact. I have experienced an ongoing example of professional pharmaceutical care (Hepler 1987; below 6.2.2) which has made me aware of the significant role a pharmacist can play in advising and supporting people living with chronic illness.

1.2.2 Pharmacy Curriculum

The second personal influence relates to my professional work as a curriculum consultant in a university Academic Development Centre. In 2001, on returning to work following the transplant, I was asked to assist the Pharmacy Faculty with the process of re-writing their curriculum documentation to meet new quality assurance requirements, and at the same time to support an interim curriculum review. During the course of this work I was constantly confronted with a discourse that positioned people living with chronic illness as a problem ('non-compliant'; 'high-risk'; 'high cost'); a business opportunity (patients on chronic medicines visit pharmacies more often); or a category (diabetics, epileptics, rheumatoids). I also came across language that was used unproblematically, and yet upon interrogation often appeared as highly problematic. For example I asked four staff members from four disciplines what the term 'rational drug use' meant, and I received four very different answers. What puzzled me was that the attitude of staff members overwhelming reflected genuine concern for patient care, while their discourse was alienating in the extreme.

During this period the lecturer in charge of the Pharmacy Administration and Practice course, with whom I worked quite closely, asked me to speak to the second year class about my experiences of living with a complex medicine regimen and especially of my experience of pharmaceutical care. I did as he requested during a single lecture session, responded to questions, and dismissed the incident from my mind. The following week the lecturer showed me some student responses to an exercise he had given them following the conversation I had had with them. Students expressed profound changes in perception of the role of a pharmacist, new insights in the experience of chronic illness, and amazement at 'how much patients knew'. I was asked to follow up this initial conversation with the third and fourth year students. In each case student response seemed out of proportion to the input³.

³ As this was not a research project at the time, unfortunately the records of this task have been lost.

In our discussion following the series of conversations I began to ask, as an educationalist, how such an unplanned, low-key, simple conversation could have had such an apparent impact on the students. During this process I came across the work of Rita Charon, Trish Greenhalgh and Brian Hurwitz on ‘narrative medicine’ (Greenhalgh 1999; Greenhalgh & Hurwitz 1999). I began to question if ‘narrative medicine’ could be incorporated into the pharmacy curriculum. Then during an early literature search I came across the following:

Truth is *partial* in that no one individual or group possesses it entirely. Knowledge comes from facts and experiences, but since our facts and experiences are inevitably limited, our truths are never total. No one of us is ever objective enough because no one of us can ever see, hear, taste, smell, or touch enough. If we wish to secure a truth greater than our own, we must converse with people whose experiences are different than our own. The truth, says Donna Haraway, emerges through "shared conversations in epistemology" (1991, p. 101). The time Descartes spent meditating would have been better spent conversing with the largest number and widest cross-section of people possible (Tong 1997:157 – 158).

The combination of the insights from narrative medicine, Tong & Haraway’s concept of ‘shared conversations in epistemology’, the sense of alienation I experienced while reading the discourse of the pharmacy curriculum documentation, and the experiences of ‘shared conversations’ with the students, combined to form a curriculum question: *Would it be possible to expose the pharmacy students to the experience of living with chronic illness in such a way that it would challenge their assumptions and move them to models of practice closer to the pharmacy practice I experienced from the transplant pharmacist ?*

My experiences convinced me that models of care for people living with chronic illness could include patient knowledge and participation without descending into the caricature of the ‘lay expert’ presented by Prior (2003). I have become convinced too, of the vital role pharmacists can, and should, play in advising and supporting optimal medication practice among people living with chronic illness. Both of these, however, require an approach to healthcare practice that is not practitioner or product centred, nor even, I will argue, patient centred, but rather relationship centred.

1.2.3 Research Question

With respect to patient medication practice and practitioner-patient interaction, pharmacy education is dominated by the biomedical approach used in traditional medical training

(Turner 1987; Robinson 2002). This approach reflects the influence of Aristotle's concept of *techne* (Pellegrino & Thomasama 1981) which suggests 'a disposition to act in a true and reasoned way according to the rules of the craft' (Carr & Kemmis 1986:32). The 'rules of the craft' as far as contemporary medicine is concerned have been encapsulated in the biomedical approach to medicine which has been dominant since the late 18th century Europe (Turner 1987; Jones 2004).

The biomedical approach locates health issues primarily within the individual, and reduces them to biochemical or physical entities, while the mind, where it is considered at all, is separated from the body or is reduced to operations of the nervous system (Marks, Murray, Evans & Willige 2000; 2.2.1 below). This approach has framed consideration of medication practice within the discourse of 'compliance' – meaning patient obedience to medical instructions (2.2.1 & 5.1. below). The failure of this approach to understanding medication practice is amply illustrated in the vast literature on *non-compliance* (Lerner 1997; Coons 2001; Cox, Stevenson, Britten, & Dundar 2002; 5.1 below). The biomedical approach has resulted in significant success in responses to life-threatening emergencies and in attending to diseases that have long threatened humanity. However the very nature of disease threat in the contemporary world has changed – chronic illness has essentially replaced acute infection as the major healthcare concern (Assal 1999; WHO 2003)⁴. This change does not appear to have been accompanied by a concomitant change in the theoretical orientation to healthcare (Davis & Fallowfield 1991a). As Ryan, Bissell and Traulsen argue with respect to pharmacy, 'It is time to question the taken-for-granted knowledge base of pharmacy, to look beneath the surface of practices and to ask whose purposes they serve, what are their unintentional effects, and how could things be done differently or better' (2004: 50).

The change in approach to pharmacy practice relating to chronic illness for which I am arguing will require more than teaching communication skills or seven-step strategies (6.2.3 Table 6-ii below). Such an approach must rest on an ontological basis other than positivist empiricism (which collapses ontology and epistemology – Bhaskar 1979, Sayer 1992; 2000; Archer 1995; 2000; and 2.2 & 2.3 below), an understanding of social theory which acknowledges human agency (Archer 1995; 2000; 2002; 2003 and 2.3 below), and on an epistemological perspective which can accommodate the social and cultural nature of

⁴ Although acute infections continue to challenge – so Avian influenza and SARS provide current threats that reflect something of Beck's 'risk society' (Beck 2000; & 3.2 below).

knowing (3.1 – 3.2 below). Moreover it will also require an understanding of professionalism that is based on a ‘covenantal relationship’ (Hepler 1987) and the implications of living in a risk society (Beck 2000; Evetts 2003 and 3.2, 3.3, & 6.2.2 below).

The initial curriculum question developed through reading Kleinman (1988), Frank (1995), the narrative medicine literature, and through conversations with Pharmacy Faculty staff and colleagues in the centre in which I work, until it appeared in the form of a tentative doctoral proposal as ‘*Developing a learning experience (intervention?) to equip pharmacists with the hermeneutic skills to attend to patient illness*’. Several iterations later, the proposal was submitted and accepted as ‘*Using film and narrative to facilitate pharmacy students’ access to the Discourse of illness*’. The underlying research question became: Is it possible, using an experiential learning approach, to facilitate pharmacy students’ epistemological access (7.2.3 below) to the medication practice of people living with chronic illness?

The prior assumptions and purposes which lie behind the curriculum question (what is most important for students to know and be able to do as a result of engagement in and with this course?) should be considered before a curriculum can be designed (Toohey 1999). I have somewhat artificially separated out those assumptions based on my experiences prior to beginning the research process (my ‘starting assumptions’), from the theoretical perspectives which arose out of the research process itself (my ‘theorised assumptions’). The *starting assumptions* which I have been able to identify were that:

1. in the biomedical process of diagnosis and treatment of chronic disease, the voice of the person living with the disorder is often silenced;
2. people living with chronic illness develop an ambivalent dependence / resistance relationship with healthcare practitioners and toward recommended therapeutic regimens;
3. the part of the therapeutic regimen most marked by ‘patient’ resistance to biomedicine is medication practice, which remains highly problematic to all concerned;
4. the failure of pharmacists to apply their particular expertise places both pharmacy as a profession and people living with chronic illness at risk, and
5. all four of the above are unnecessary and avoidable.

The *theorised assumptions* which have informed (and were developed through the process of) this study are outlined below.

1.2.4 Structure of the thesis

The starting assumptions serve to structure the thesis, although inevitably earlier chapters provide the theoretical foundation for later chapters while the later ones locate the theory more specifically in pharmacy practice and education for pharmacy practice. The fifth starting assumption noted above provides the impetus, while the fourth provides the focus for the study.

In reading for the study the concerns that remained uppermost related to my own *knowing of* both terminal and chronic illness, and the *knowing about* these experiences as presented within the pharmacy course documentation with which I was working in the course of my curriculum consultancy⁵. As I began to read around the concept of illness experience, I came across Kleinman's (1988) critical interrogation of the meaning and experience of chronic illness. In these comments Kleinman suggests the direction for an epistemological critique:

Social reality is so organised that we do not routinely inquire into the meanings of illness any more that we regularly analyze the structures of our social world. Indeed, the everyday priority structure of medical training and of health care delivery, with its radically materialist pursuit of the biological mechanism of disease, precludes such inquiry... (Kleinman 1988:8).

This leads to the situation in which:

...medical metanarratives are normative scientific, social, and cultural narratives that shape the meaning of our experiences. By defining health, illness, care, and patienthood in terms of disease conditions, they tend to suppress subjectivity and the uniqueness of experience, dominating and objectifying the person who is the patient (Sakalys 2003:230).

Because questions about epistemology lead to prior questions about ontology (Bhaskar 1979; 2002; Byrne 2002), human agency and social structure (Bhaskar 1979; Archer 2000; 2002; 2003), these passages served to bring my epistemological questions into conversation with ontology and social theory.

The theoretical arguments developed in Chapters Two to Six of the study propose an understanding of what theoretical⁶ perspectives could best inform pharmacy education, especially with respect to pharmaceutical care of people living with chronic illness. The experiential learning approach to teaching and learning which I propose in Chapter Seven, is

⁵ I am fully aware that course documentation does not fully reflect the curriculum as a whole, and that individual lecturers imbue any curriculum with their own reflexive agency in ways that may resist and transform the discourse of the documentation.

⁶ Theory here is understood as 'an examined conceptualization' (Sayer 1992:51).

built on these perspectives. At the end of each section below (1.2.4.1 – 1.2.4.7) I will add bullet-point summaries of the essential concepts relating to the development of the curriculum approach I propose in Chapter Seven.

1.2.4.1 Understanding what is real

Chapters Two and Three are concerned with a consideration of the philosophical underpinnings of biomedical and psychosocial perspectives on healthcare. In Chapter Two I review the critique of the empiricist/positivist underpinnings of the biomedical model (Annandale 1998), and argue that the critique offered by critical realism is the most cogent and most useful for supporting an alternative ontological perspective on healthcare (Bhaskar 1979, 2002; S. Williams 2000a; 2.2 & 2.3 below). I then propose that Margaret Archer's *social realist* understanding of human agency provides a firm basis for developing an understanding of both patient and pharmacist agency, and affords a challenge to the constraints of social structures surrounding healthcare (Archer 1995; 2000, 2002, 2003; and 2.3.3 below)⁷. In summary then, I work from:

- a **critical realist** understanding of reality (natural and social) as analytically stratified and existing independently of our knowing of it, which argues that causality is not reduced to laws relating to constant conjunctions of events, but can at best be understood as causal tendencies within open systems (2.3.1 – 2.3.2);
- a **social realist** perspective which proposes an analytical dualism in examining social structure and agency, the primacy of practice in our relationship with the world (natural and social), and the role of reflexivity in human identity and agency. Such an approach 'readmits' the biological body back into understandings of illness (S. Williams 2000a; & below 2.3.3 – 2.3.5).

1.2.4.2 How do we come to know?

In Chapter Three I argue that the sociocultural epistemological perspective proposed by Wells (1999) is congruent with critical and social realism. I argue that such a perspective with its understanding of knowing as a geo-historical process that is cumulative as distinct from additive and is rooted in praxis, offers a sound epistemological basis for knowing in the healthcare / patient space. In summary I propose using:

- a **sociocultural epistemology** which is congruent with social realism and argues for the roles of 'experience,' 'information,' 'knowledge-building' and 'understanding' in

⁷ Note that Archer's social realism is rooted in critical realist ontology.

knowing. Such an approach understands the role of discourse in learning and practice, and recognises discourse as causative (3.1.1 – 3.1.4; 2.3.2; 2.3.3 – 2.2.5 below).

1.2.4.3 Health, disease, illness and sickness

Chapter Four moves to a sociological consideration of the concepts of ‘health,’ ‘disease,’ ‘illness,’ and ‘sickness’. I argue that neither health, nor disease, nor illness, nor sickness, are unproblematic concepts in which commonsense understandings are adequate. Using insights from the sociology of health and illness, I argue that any model of healthcare practice focused on disease alone is reductive and insufficient in the age of *supercomplexity* (Barnett 2000 a,b,c; and 3.2, 7.2.1 & 7.2.2 below). Equally, relying simply on the patient’s perspective (illness) or society’s construals (sickness) will similarly produce distorted healthcare practices. What is needed is a conceptual model in which the voices of biomedicine, the person who is ill, and society are all heard. In the light of this discussion, I argue that chronic illness is particularly illustrative of supercomplexity, and requires a holistic response. In summary I accept that:

- **understandings of health, disease, illness and sickness** are theoretically problematic social construals, potentially underpinned by different ontological and epistemological perspectives. If these understandings are used in a paradigmatic way, they do not permit a holistic understanding of healthcare (Chapter 4).

1.2.4.4 Framing medicine-taking

In Chapter Five I offer a critique of the biomedical approaches of both ‘compliance’ and ‘adherence’ to understanding medication practice, based on a consideration of some of the extensive literature from medical, pharmaceutical, sociological and critical health psychology literature (5.1). I then propose that the recent development of the concept of *concordance* (Cox, Stevenson, Britten, & Dundar 2002; Bissell 2003; Bissell, May & Noyce 2004), while not unproblematic (Heath 2003; Jones 2003; Armstrong 2005) holds the most promise for understanding and informing healthcare practice with respect to medication practice in chronic illness (5.1.4). This chapter serves to narrow the focus of the study toward a specific consideration of pharmacy practice. In summary my:

- **understanding of medication practice** rejects the technical lenses of compliance and adherence (5.1.1 – 5.1.3), and argues for the primacy of concordance as an interpretive lens for negotiating optimal medication practice, especially with respect to people living with chronic illness.

1.2.4.5 Pharmacy as a profession

Chapter Six begins with adopting the understanding of *pharmacy practice* proposed by Wingfield, Bissell and Anderson (2004) as ‘those activities of pharmacists that most closely and directly impact on or interact with the final consumer of medicines, be they patients or users’ (2004:2384). My consideration of pharmacy thus attends to this aspect of the pharmaceutical profession, rather than to administrative or industry-related aspects. I offer a socio-historical overview of the development of pharmacy as a profession, including an acknowledgement of the debate around whether or not pharmacy is a profession (6.2). Arising out of this discussion I propose the adoption of Evetts’ (2003) understanding of ‘profession’ (below 6.2.3) and argue that such an understanding may serve to better facilitate a shift from a product-focussed understanding to a relationship-centred approach of pharmaceutical care as the basis for the profession of pharmacy (6.2.3 – 6.2.4). In summary I argue that:

- an **understanding of pharmacy practice** based on a revision of Hepler’s original covenantal relationship (Hepler 1987) and Evetts’ (2003) understanding of profession in a risk society (6.2.2 & 6.2.3 below) may better enable pharmacists to use their expertise to advise and support people living with chronic illness.

1.2.4.6 Experiential learning and epistemological access

In Chapter Seven I propose an **approach to teaching and learning** in the pharmacy practice curriculum. In line with the understanding of *competency* expected of higher education courses by the South African Qualifications Authority (SAQA 2000:10 and Glossary), this approach focuses on developing the foundational, practical and reflexive competency of pharmacy students with respect to the pharmaceutical care of people living with chronic illness. The pharmaceutical and pharmacological aspects of the foundational and practical dimensions of competency are the concern of other courses in the Bachelor of Pharmacy, and so these are referred to and integrated into the course where relevant. The course focuses mainly in the development of reflexive competence through experiential and affective learning.

1.2.4.7 The case study

Having argued for a experiential approach to teaching and learning to facilitate pharmacy student’s epistemological access to the medication practice of people living with chronic illness, in Chapter Eight I use a case study, based on a course taught as a fourth year elective for Bachelor of Pharmacy students, as an illustration of how such an approach may look in practice (8.1.1 below). The course included the use of fictional film (*Wit* – Nichols 1998);

students' interviews with people diagnosed as suffering from rheumatoid arthritis; and the use of online journals to facilitate students' critical reflection on aspects of their practice. I used a critical approach to discourse analysis based on Johnstone (2002; below 8.3.6 & 8.3.7) to examine some of the texts produced by the students who took the course. In this examination I attempted to identify the discourses underlying the way students construe their role as pharmacists, the way they construe the experience of illness and the way these construals affect their role in advising and supporting medication practice (8.3.2 & 8.4 below).

1.2.5 Beginning the process

Hoey (2002) tentatively suggests that central to any discussion of how healthcare professionals and sick people differently conceive of the concern that brings them together, is a matter of epistemology: 'Is the problem simply that patients and epidemiologists [or any other healthcare practitioner] know, and want to know, different things?' (Hoey 2002:157). Are disease and illness simply different epistemological perspectives on the same thing? My argument is that 'knowing' is not merely a matter of epistemology, but presumes an underlying understanding of 'the way the world is'. Failure to consider our ontological perspective may simply reproduce the problem which Hoey so neatly proposes. It is thus to a consideration of the ontological and social theory perspectives which inform this study that I now turn.

Chapter 2 : Shaping Perspectives: Ontology, Structure and Agency

[T]here are two intellectual gangs against whom we [critical realist social scientists] are working. One of those gangs we will call reductionists and the other we will call innumerates. The first gang can count but don't know what they are counting, why they are counting, or what to do with what they have counted when they have counted it. The second can't count, won't count, and assert that counting is a vile and perverse activity which ought not to be allowed. The reductionists are positivists but don't use the term all that much. The innumerates use positivism as pejorative label for all quantitative work... (Byrne 2002:14 – 15).

2.1 Introduction

Healthcare practice that is dominated by biomedicine has been challenged by patients¹, healthcare practitioners, sociologists of health and illness and health psychologists (Turner 1987; Kleinman 1988; Gwyn 2002; White 2002; Marks 2000). Criticism has been levelled primarily at the reductive, and at times instrumentalist, perception of health and illness which has resulted from biomedicine's dominance of healthcare. One specific area of concern has been the inadequacy of the biomedical perspective in providing understanding of the practitioner-patient interaction.

[The biomedical approach] has the consequences of neglecting the patient as a person, underestimating the importance of communication, and not according the respect to patients that they merit and must be given for their long-term benefit.... While the model may work with comatose or anaesthetised patients, in most other circumstances the fallacy of the model becomes obvious.... (Davis & Fallowfield 1991a: 15 – 16).

Criticism has not been limited to the practice of medicine, but has also questioned pharmacy and nursing practice, and health care education (Callaghan 1998; Greenhalgh & Hurwitz 1999). As far back as 1967, leading members of the pharmacy profession registered strong protest at the deleterious effect that pharmacy's subservience to biomedicine was having on both pharmacy education and pharmacy practice (Hepler 1987). In response to the circumstances which gave rise to this, Hepler, a clinical pharmacist, proposed the

¹ Please see Glossary for an explanation of my use of 'patient'.

‘philosophy’ of pharmaceutical care (Hepler 1987) which has gradually become the rallying cry of those seeking to revitalise a disenchanted profession (Editorial, *Pharmacy Journal* 1997). However, pharmaceutical care appears to be more a ‘standard’ for professional practice than a philosophy of pharmacy, as a glance at the ‘Seven Elements of Pharmaceutical Care’ will show (Editorial, *Pharmacy Journal* 1997:903. See also below 6.2.3 Table 6-ii). In the light of this growing dissatisfaction with biomedical dominance, calls have come for a change in the philosophical basis of healthcare practice and, most specifically, of healthcare education (Robinson 2002 – who calls for a new philosophy of pharmacy education – Bergum 2003; Burger 2001; Callahan 1998; Greenhalgh & Hurwitz 1999).

Criticism of pharmacy from outside the profession itself has come most strongly from medicine. Medicine’s intent does not appear to have been as much to re-theorise pharmacy as a profession, but rather to restrict its role, limit its autonomy, or even to question its value (Gilbert 1998; 2001; Edmunds & Calnan 2001). Until recently health psychologists and sociologists, with the possible exception of Denzin & Mettlin (1968) and Turner (1987), have paid scant attention to pharmacy in general and to pharmacy education in particular. As sociological critique of the professions gains momentum however, pharmacy is beginning to come under scrutiny (Ryan, Bissell & Traulsen 2004; Traulsen & Bissell 2004).

In this chapter and the next, I will provide a consideration of the philosophical and social-theoretical perspectives that shape this study. The following sections provide a synopsis of the biomedical perspective followed by those of its psychosocial critics. I then propose that *critical realism* provides a more suitable ontological basis for the consideration of pharmacy practice than do either the empiricist-positivist ontology underpinning biomedicine, or the social-constructionism of traditional psychosocial approaches. Acceptance of a critical realist ontology demands a congruent social theory, and I propose that Margaret Archer’s *social realism* provides an understanding of *human agency* congruent with critical realist ontology (Bhaskar 1979; 2002; Archer 2000; 2002; Harvey 2002). The study deliberately seeks a *critical* perspective because it is concerned with:

educational problems and issues [that] arise not only as *individual* matters, but as *social* matters [that require] collective or common action if they are to be satisfactorily resolved. The outcome of critical research...is not just the formulation of informed practical judgement, but theoretical accounts which provide a basis for analyzing systematically distorted decisions and practices, and suggesting the kinds of social and educational action by which these distortions may be removed (Carr & Kemmis 1986:31. Italics in the original).

I have deliberately eschewed the use of the word ‘paradigm’ in favour of the idea of ‘perspective’. ‘Perspective’ gives a sense of ‘having a place to stand’, a ‘vantage point’ from which the world is viewed. It implicitly acknowledges that other perspectives will view the world differently. Some of these views may be more or less helpful, but not necessarily oppositional. Like Thorne, Kirham and Henderson (1999), I find the post-Kuhnian discourse of paradigms ideologically loaded and fractious. The use of the discourse of paradigms appears to require a commitment to incommensurability which privileges one version of ‘truth’ / power / knowing over others, and inhibits a holistic, multi-disciplinary approach to increasingly complex problems (Sayer 1992). Ironically this often results in exchanging one version of hegemony for another (Thorne *et al.* 1999; Phillips 2000; Bhaskar 2002). A rejection of paradigm discourse does not result in a *judgemental* relativism, which would mean that all perspectives are equally valid in all contexts (Bhaskar 1979), however it does accept an *epistemic* relativism which acknowledges that ‘all beliefs are socially produced, so that all knowledge is transient, and neither truth-values nor criteria for rationality exist outside of historical time’ (Bhaskar 1979:73).

2.2 Perspectives on healthcare

The critique of biomedicine has been shaped predominantly by constructionist perspectives on disease and healthcare (Playle & Keeley 1998; Woodward & Watt 2000), although the critique often had a critical edge made evident in an increasing awareness of underlying ideology (Turner 1987; Williams, S. 1999; Gwyn 2002). A central focus of the critique remains the healthcare practitioner / patient space, calling for the re-inclusion of both society’s and the individual patient’s voices into discussions about healthcare and disease (Turner 1987). This critique has resulted in calls for a holistic, non-dualist approach to understanding and practising healthcare (Kleinman 1988; Porter & Ryan 1996; Callahan 1998; Gwyn 2002; White 2002; Prilleltensky & Prilleltensky 2003). The crucial philosophical issue revolves around what shape this non-dualist perspective should take.

As Hoey (2002) and Robinson (2002) suggest, establishing a new perspective towards healthcare is an epistemological problem. Epistemology, however, no matter how tacitly, presumes ontology (Bhaskar 1979; 2002; Byrne 2002). Ontological assumptions in any discussion of health and illness must then be made explicit. Since the role of philosophy is ‘to show what must be the case for the ensemble of scientific activities to be possible’

(Bhaskar 1979:8), then philosophical perspectives are at the heart of the theoretical concerns which inform the pharmacist-patient space: the concepts of disease, illness, and pharmacy practice (Turner 1987; Traulsen & Bissell 2004). Any consideration of preparation of people as pharmacists needs, therefore, to be clear about its epistemological and ontological grounding.

There has been a tendency to resort to caricature in the often acrimonious debate between the biomedical and the psychosocial perspectives of healthcare. Indeed the postmodernist turn in the ‘sociology of health and medicine...has fabricated its own privileged perspective in binary opposition to what is positioned as the “biomedical model”...’ (Annandale 1998:46). If some way cannot be found to bring these two perspectives into dialogue, then healthcare and healthcare education in particular may well be compromised (Callahan 1998; Gwyn 2002). While the debate is wide-ranging, this study is primarily concerned with the implications of the debate as it relates to the biomedical dominance of the *act of medicine*, or more particularly the *act of pharmacy*. By ‘act of medicine / pharmacy’ I mean the moment where medical / pharmaceutical sciences meet human experience in the interaction between healthcare practitioner and a patient. Pellegrino and Thomasama express this concern thus:

The patient presents himself in a state of wounded humanity. He has lost some of his freedom since he must come to the physician; he must give consent when he is in pain and discomfort, and he does so in the presence of an information gap which can never be closed fully. *Medical science, therefore, becomes medicine only when it is modulated and constrained in unique ways by the humanity of the physician and patient... No simplistic neo-Cartesian reduction of medicine to sciences of the mind, arithmetically added to science of the body and tied together with a ribbon of moral science, is adequate to explain this synthesis* (Pellegrino & Thomasama 1981:24. Italics added).

The following sections serve first to briefly outline the *biomedical* and *psychosocial* perspectives on healthcare practice. Inevitably this discussion reflects the paradigmatic nature of this debate, although I will argue that what is needed is an epistemological conversation between the two perspectives. I then argue for the adoption of a revised *biopsychosocial* perspective suggested by Borrell-Carrió, Suchman, & Epstein (2004) rooted in the non-dualist *critical realist ontology* (Bhaskar 1979; 2002) which provides a ‘middle way between positivism’s fading path and the unchecked caprices of hermeneutic analyses... the ameliorative “third path”...’ (Harvey 2002:163). Epistemologically, as the

following chapter describes, this study is located within a *sociocultural perspective* which presumes a non-dualist ontology (Packer & Goicoechea 2000) and has a concern for *discourse* (Wells 1999).

2.2.1 Biomedicine and healthcare

Biomedicine's ontology is realistic and its epistemology is positivist. There is a lack of awareness that the construction and evaluation of "scientific data" are social processes. The understanding of facts as independent from theory underplays society's role in the construction of the means through which disease is studied and treated. The location of disease in the individual body exonerates society from any responsibility in the etiology [*sic*] of disease (Flic 2004:1276).

The three philosophical assumptions that appear to have underpinned biomedicine are:

- that reality precedes and exists independently of our knowing (Byrne 2002);
- the existence of mind-body dualism (Annandale 1998);
- a reductive biological and/or individualistic theory of causality regarding disease (Mishler 1981; Armstrong 2000; White 2002).

Biomedicine's epistemological concern is for how knowledge may be obtained in order to facilitate prediction and control ('diagnose and treat' - Callahan 1998:85). The principles that facilitate 'diagnosis and treatment' in biomedicine include:

- 1) a reductive assumption that 'health and disease are natural phenomena which exist in the individual body, rather than the interaction of the individual and the social world' (Annandale 1998: 6);
- 2) a tendency to reify measurement (Gillett 2004), which Byrne (2002:15) describes as 'the things we measure exist and measurement describes them as they are';
- 3) a tendency to equate diagnosis with 'obtaining the facts' in a way similar to gaining insight about the world through experimentation. This is based on the principle that the existence of anything which cannot be tested / observed experimentally is in doubt (a principle of so-called 'Evidence Based Medicine'- Greenhalgh 1999; Woodward & Watt 2000);
- 4) the view that facts are value-free or that facts 'speak for themselves'. As Wax notes, 'once this thesis is regarded as true, then issues of health are displaced by the technological and physiological, detached from the complexities of human existence' (2003:125);
- 5) the position that any effect has, or can be reduced to, a single cause which if it exists must result in that effect. If a specific cause is not present then a consequent

specific effect cannot occur. This bears direct relation to the biomedical concept of *specific aetiology* – one cause for each disease (Mishler 1981; Armstrong 2000; Byrne 2002). This helps form the link between diagnosis and treatment (Armstrong 2000);

- 6) the view that the healthcare professional (HCP) is objective and so in her/his diagnosis includes only objectively obtained data and rejects other possibilities using Popperian falsification (Williams & Popay 1994; Greenhalgh 1999);
- 7) the twin assumptions of the superiority of the HCP's knowledge by virtue of her/his expertise (Davis & Fallowfield 1991a,b), and of the inherent appropriateness of the prescribed treatment regimen based on the notion of diagnosis identified in (3) and (6), which underpins the concept of *patient compliance* (Rantucci 1990).

These ontological and epistemological assumptions have allowed medical science to achieve remarkable success with respect to the treatment of acute conditions. With respect to care of persons experiencing illness, however, they lack what Sayer terms 'practical adequacy' in that they do not 'generate expectations about the world [in this instance the social world of the care of persons] and about the results of our actions which are actually realised' (Sayer 1992:69). Underpinned by objectivist assumptions, biomedicine has 'created an environment uncongenial to practical wisdom, humanistic relations, compassionate caring' (Wax 2003:120 – for example, see the discussion on medicine-taking practice, 5.1 below). These concerns are central to the social science critique of the biomedical perspective on healthcare (Tang & Anderson 1999; Gywn 2000; White 2002) and mirror the concerns raised by Engel in 1977 in his proposal of the biopsychosocial model of healthcare (Borrell-Carrió *et al.* 2004). They also have particular bearing on the interests of this study with regard to chronic conditions, pharmacy practice, and pharmacy education (Turner 1987; Kleinman 1988; Toombs 1995; Callahan 1998; Assal 1999; Tang & Anderson 1999; Traulsen & Bissell 2004):

Pharmaceutical knowledge is based on exact sciences and has been developed by widely accepted procedures of experimentation. Pharmacy leaves little scope for hermeneutics.... The paradox is that pharmacology may be overdeveloped as a science of drugs but underdeveloped as an interpretive skill with respect to patient wellbeing (Turner 1987: 145 – 146).

The psychosocial critique of biomedicine has challenged each of the principles enumerated above, not so much in terms of medical science *qua* science, but rather

as healthcare practice. Much of the critique is rooted in the rejection of positivist dualistic assumptions driving healthcare practice (Scrambler 2001). The dualism inherent in the separation of mind and body offers a common-sense heuristic based on empiricism. ‘Common-sense’ ways of thinking, however, act to sustain ideological positions (Fairclough 1995). For example, the dualism of biomedicine does not allow for causal relations between mind-body. This means that patients’ ‘sense’ of how things are is easily ascribed to the emotional realm, and therefore as lacking epistemological purchase in diagnostic and/or therapeutic decisions. Ironically biomedicine is at pains to account for the ‘placebo effect’ in drug trials, and yet the acknowledgement of such an effect presumes a mind-body connection (Woodward & Watt 2000; White 2002; Borrell-Carrió *et al.* 2004).

The doctrine of specific aetiology which is rooted in this dualism fails to recognize the individual in context (Hampton 2002) and so ‘fails to account successfully for the multifactorial effects of the broader social environment on susceptibility to disease through factors such as stress and nutritional deficiency’ (Annandale 1998:7). It also fails to address the needs of the patient as a person within society:

In the narrow biological perspective of the biomedical model ... disease is reconfigured *only* as an alteration in biological structure or functioning. When chest pain can be reduced to a treatable acute lobar pneumonia, this biological reductionism is an enormous success. When chest pain is reduced to chronic artery disease for which calcium blockers and nitroglycerine are prescribed, while the patient's fear, the family's frustration, the job conflict, the sexual impotence, and the financial crisis go undiagnosed and unaddressed, it is a failure (Kleinman 1988:6 *Italics original*).

Biomedicine’s claim to be concerned ‘only with the facts’ fails to acknowledge that observation is theory laden (Harari 2001; Hampton 2002; Wax 2003; Borrell-Carrió *et al.* 2004; Gillett 2004). Social factors have significant influences on the way in which medical science selects which ‘facts’ to concentrate on in developing responses to health concerns (Annanadale 1998; White 2002). Even within diagnosis decisions relating to an individual, the ‘facts’ selected to arrive at a diagnosis have been shown to depend on the perspective of the medical practitioner – the micro level of biomedicine. Geisler refers to Lesgold’s (1988) research undertaken among radiologists, in which novice and expert radiologists interpreted x-ray films in very different ways. The expert radiologists used ‘information’ that was not available to them from the film, but was related to the individual patient, as well as

context-specific features of the specific x-ray film. The novice radiologists applied ‘general models of anatomy’ to the interpretation of the films (Geisler 1994:63). In this way a socially-mediated element (judgement based on experience) was shown to influence the selection of facts to arrive at a diagnosis (Geisler 1994). In this understanding ‘experience’ is ‘not what happens to a person, but the meanings that are constructed in the course of participation in the succession of events that make up his or her life trajectory’ (Wells 1999:84). Diagnosis is revealed as a construction rather than a precise experimental finding (Brown 1995; Hampton 2002). This epistemological concern for what counts as knowing, or what ‘facts’ count, especially in treatment decisions for chronically and terminally ill patients, forms one of the sites of disagreement between biomedicine on the one hand and health psychologists, sociologists of medicine, patients and care-givers on the other (Williams & Popay 1994; Annandale 1998; Marks 2000). The claim to objectivity which characterizes biomedicine serves to silence the pejoratively-labelled subjective experience of the patient and lends itself to algorithms dominating over care (Williams & Popay 1994).

In the era of biomedicine, physicians claim the authority of *science*, but science is abstract and the problems of the patient are concrete, particular, individual. With her own body, the sensitive patient has the experience of a lifetime, to be voiced as stories, whereas the physician typically finds the stories irrelevant as he attempts to fit the particular manifestations onto the template of a disorder for which biomedicine furnishes a treatment that has a scientific (‘evidence-based’) treatment. When the patient rejects that treatment, the physician speaks of ‘non-compliance’. The asymmetric power relationship is revealed in the fact that the patient may not judge physician or nurse as *non-complying* (Wax 2003:125 *Italics original*).

These and similar criticisms call for a consideration of healthcare issues from a psychosocial perspective which would attend to the whole person within her/his context, and not merely focus on the biological factors of disease. As Nettleton points out, both medicine and the sociology of health and illness are concerned for the body: ‘But this is not the passive anatomical frame that was the focus of biomedicine, but the body that is capable of social action and its interpretation’ (1995:11).

2.2.2 *The psychosocial perspectives to health care*

Although the psychosocial perspectives of healthcare share common positivist philosophical beginnings, since the 1960s they have been largely shaped by interpretivist perspectives which seek to interpret and understand meaning in health and illness at both individual and

societal levels respectively (White 2002; Murray & Campbell 2003). The challenge to biomedicine's positivism was initially clearly articulated by the Marxist-inspired critical turn within sociology beginning in the 1970s. Following this, health psychology and the sociology of health and illness have been steadily brought closer together.

2.2.2.1 The sociology of health and illness

Since Gerhardt (1989), Annandale (1998) and White (2002) provide thorough reviews of the development of sociology's interest in health, illness and medicine, I shall present only a brief overview. The terms 'sociology of medicine,' 'sociology of health,' 'medical sociology,' and combinations of these such as 'sociology of health and illness,' are used interchangeably in much of the literature (for example, Annandale 1998:33 – 60; White 2002:34 – 52). It is clear, however, that these terms carry potentially different interpretations of the task. 'Sociology of health' implies a far wider purview than 'sociology of illness', for example, while 'medical sociology' suggests a concern for medicine such as that noted by White with respect to 'sociology *in* medicine' (White 2002). I have chosen to use the term 'sociology of health and illness' as it reflects a wider concern for both the agents and structures involved in healthcare *and* those involved in illness. Where I reflect the views of an author or authors, I shall only retain the term used by that author if it is important to distinguish her/his perspective from mine.

It is generally accepted that the sociology of health and illness began after the Second World War and was well established in North America and Europe by the 1960s (White 2002). In the 1950s Talcott Parsons' structural functionalist perspective dominated North American sociology. Parsons' use of medical practice as a particular exemplar helped establish sociology in close alliance with biomedicine, despite sociology's rejection of illness as simply physiological (Gerhardt 1989; Annandale 1998). Thus 'sociology of medicine' adopted biomedicine's primary concern for disease and health, rather than illness (Parsons 1951; Gerhardt 1989; Annandale 1998; Shilling 2002). Contra Marx, Parsons argued that health, not economics, was a fundamental social requirement (Parsons 1951; Gerhardt 1989). Since disease was regarded as organic, and illness a form of 'deviance from a norm', sociological research could best serve by trying to find solutions to patient non-compliance, and medicine determined the agenda (Turner 1987; White 2002).

The sway of structural functionalism over the sociology of health and illness was challenged by the 'anti-psychiatry' movement. This movement, led by Becker (1953 & 1963), Strauss (in 1959 & 1963), Freidson (first in 1970), Sedgwick (in the UK in 1982) and Szasz (in the US in 1960), began in the 1950s and extended into the 1980s. Social interactionists such as Mead, Goffman and Strauss then began to draw attention to the need for a more nuanced understanding of agency and structure. This led to the healthcare practitioner-patient interaction receiving greater attention, especially with respect to chronic illness. This approach was highly critical of power relations involved in medicine, and resulted in the social labelling of illness as a professional construct and the critique that medicine should be seen as complicit in social control (Gerhardt 1989).

Until the late 1950s medicine had been concerned with acute conditions ranging from influenza, tuberculosis and gastroenteritis, to the ravages of war. The importance of these conditions reduced as general economic conditions and health awareness improved, and new technologies arose to attend to acute conditions (Nettleton 1995). By the 1980s common causes of death had little to do with the 'germ theory' of disease that had so far dominated both biomedicine and the sociology of health and illness (White 2002). The most common causes of morbidity / mortality became cardiac conditions, cancers, cardiovascular lesions (strokes; aneurysms) often related to high blood pressure, and violent death (Turner 1987; Nettleton 1995; Yach & Hawkes 2004). This required a change in both the understanding of the disease concept, and in the understanding of the interaction between environment (including society) and disease (Turner 1987; White 2002).

Neo-Marxist critique of both economic links to disease and the commodification of the body through capitalist involvement in health care, coincided with the changes in the nature of disease / illness (Turner 1987; Annandale 1998). The central figure in the changing emphasis of sociology of health and illness was Foucault, with the publication in English of *The Birth of the Clinic* in 1975 (Gerhardt 1989). Characterised by concepts such as the 'panoptic gaze of medicine', the 'surveillance society', and illness as ideological constructs, the sociology of health and illness began to adopt constructionist and/or overtly post-Marxist critical perspectives (Gerhardt 1989; Annandale 1998; Woodward & Watt 2000). Beck and Giddens' concepts of a 'risk society' increased awareness of the individual standing alone against the risks of modernity and post-modernity, and brought the individual into greater focus within the sociology of health and illness (Annandale 1998).

The ontological understandings underpinning the sociological perspectives of healthcare vary widely. Parsons' structural functionalism insisted on an element of social construction in understanding illness and questioned the biomedical model's positivist links, but retained an objectivist value-neutrality with regard to illness (Turner 1987; Annandale 1998; White 2002). Constructionism in its various guises features strongly in sociological studies related to health and illness (Appleton & King 2002) and is generally regarded as reflecting relativist ontology with regard to the social sciences, and in the case of radical constructivism, the natural world as well (Phillips 2000). Constructionists reject causality as a valid concept on the basis that cause and effect cannot be effectively separated (Phillips 2000; Benton & Craib 2001; Appleton & King 2002). Post-positivism regards reality as existing external to the knower, but recognises that reality may only be partially known. Related to this is a concept of causality which posits 'that natural laws do exist, behaviour can at best be predicted probabilistically, and thus causality can be only partially understood' (Appleton & King 2002: 643). The range of critical perspectives share one or other of these ontological positions, with the possible exception of critical realism to which I shall return later.

Despite its critical interests, the sociology of health and illness does not presume to tell healthcare practitioners how to engage in the *science* of medicine; it does, however, discover matters of interest in the *practice* of medicine. Sociology's concern is to examine the relationships between individuals (as agents) and society and vice versa, and the relationships between groups within society, and between society and those groups (White 2002). When the sociology of health and illness encounters an individual its proper questions relate not to why the person is sick in a biological sense, but what 'set of structures' has influenced, and continues to influence, the life chances of members of the group to which she / he belongs (White 2002). While 'structure' has been central to social theory from its inception, the term is frequently undefined. Sayer argues for a critical realist understanding of social structure as 'a set of internally related elements whose causal powers, when combined, are emergent from those of their constituents' (Sayer 2000:14). So for example, among those social structures, are those that label and treat illness – the healthcare professions and the healthcare industry. The critical turn in the sociology of health and illness demonstrates the way structure, so understood, can support for example, robust questions about what lies behind the labelling of disease, the social

implications of medicalization² in and of society, the power which has accumulated around the healthcare professions as a result of their role as experts, and how economic and political structures impact on health and illness (Turner 1987; Kelleher, Gabe & Williams 1994; White 2002).

2.2.2.2 Health psychology

Health psychology began as a distinct area of research in North America during the 1970s with a strong emphasis on individual responsibility for health, and with a direct interest in the health consumer/healthcare provider transaction (Marks 2002). As health psychology evolved, it divided into four interest areas as shown in Table 2-i below:

Perspective	Methodology	Interests
Clinical Health Psychology	biopsychosocial; post-positivist; realist	healthcare system; education; closely allied to medical profession
Public Health Psychology	pluralist (post-positivist emphasis)	epidemiological studies; primary health care; mass communication about health issues; doctor-patient communication
Community Health Psychology	socio-constructivist; ethnographic; critical	community development; proactive focus on health promotion; local focus
Critical Health Psychology	critical – willing to use any methods subject to critical motive	social structures; challenges power; seeks equality of health resources; national / global focus

Table 2-i: Perspectives of health psychology (based on Marks 2002: 12-13)

As Table 2-i suggests, the philosophical underpinnings of the range of health psychologies, as with the sociology of health and illness, extend from post-positivist biopsychosocial, through the phenomenological / hermeneutic to the critical (Marks 2002; Öhmann, Söderberg & Lundman 2003; Murray & Campbell 2003). Health psychology has been primarily concerned with the individual, taking some cognizance of her / his context, while the sociology of health and illness has been concerned with the social, taking cognizance of the individual. Recently the critical turn within health psychology has led to an increasing concern for social factors (Marks 2002; Murray & Campbell 2003), while feminist and disability theorists' insights into embodiment have deepened sociology's awareness of the individual (S. Williams 2000a). The closing of the interest gap is particularly apparent in critical health psychology (Prilleltensky & Prilleltensky 2003).

² See 'Glossary'

Prilleltensky and Prilleltensky argue that the critical and community health psychologists' turn to group-based work is both insufficient and too late as 'most risk conditions do not reside within the individual but within the social and physical environments. As a result, preventative efforts for people at risk have proven minimally effective....' (Prilleltensky and Prilleltensky 2003: 208). Critical health psychology has thus begun to join the sociology of health and illness in asking questions of the relationships between academic institutions and the healthcare industry, including the pharmaceutical industry (Kelleher *et al.* 1994; Marks 2002). This blurring of the distinction between the concerns of the two disciplines is illustrated in a challenge to health psychology by Murray and Campbell, to:

move from the standpoint of the detached observer to that of the socially committed....It is important to challenge the dominant ideas of the discipline and to expose how not only do they individualize and reductify [*sic*] health and illness and ignore social deprivation, but they also position health psychology on the sidelines of the movement to improve health (2003:233).

2.2.2.3 The Biopsychosocial Model

Both the sociology of health and illness and health psychology challenge the hegemony of biomedicine in healthcare. In 1977, in the first major response to this challenge, Engel proposed what he termed the *biopsychosocial model* (Marks, Murray *et al.* 2000; Borrelli-Carrió *et al.* 2004). Marks criticises the biopsychosocial perspective to healthcare practice as little more than 'a combination of factors that produce health and illness' (American Psychological Association definition in Marks 2002:11), and as Marks notes:

[A] combination of factors doth not a model make. The BPSM [biopsychosocial model] is a piece of technical jargon for a set of beliefs about health and illness that values psychology and culture....The BPSM has given good service, as a cover-term for beliefs and values, but as a Trojan horse to reform biomedicine, the BPSM needs reconstruction (2002:11).

What the BPSM lacks is a critical philosophical foundation. Marks argues that the BPSM still retains biomedicine's dualism, and disease is essentially understood as biological, with scant attention to socio-cultural influences on disease labelling. The BPSM offers at best what Cornish terms 'an aggregative model' in which biological, psychological and social variables are collected together in an unstructured fashion (Cornish 2004).

Ironically, one of the central interpretivist criticisms of biomedicine could apply just as well to the psychosocial approaches, although in mirror image. As Bhaskar repeatedly points out, hermeneutic and even critical theory perspectives end up with a dualism which in most cases mirrors positivist / empiricist perspectives by collapsing ontology into

epistemology (1978; 1979; 1994; 2002). In the instance of healthcare, the human body becomes an epistemological construct, which to misuse Spelman's term (S. Williams 2000a:804) reflects a 'somatophobia' and the result is simply another dualist mind-body distinction. This has resulted in a situation within psychosocial perspectives in which:

...a panoply of bodies now, quite literally, litter the field, from Falk's (1994) 'consuming body'... to Martin's (1994) 'flexible' body... Becker's (1984) 'tremulous' body to Sheldrick's (1997) 'leaky' body.... Foucault's (1973, 1979) 'discursive' body and 'technologies of the self' (1988), Merleau-Ponty's (1962) 'phenomenological' body and Baudrillard's (1988) 'hyperreal' body... (S. Williams 2000a: 799).

The body quite obviously missing from the list is the biological one, which, it seems, has been left to biomedicine (Lupton 1994; S. Williams 2000a). While the need to uncover ways in which the body is construed in relation to health care is vital, this uncovering of the body *must* include the biological (Schilling 1999; Lawton 2003). Those living with chronic illness and disability have to do with a biological reality that remains obdurately resistant to rarefied philosophical-psychosocial debate (Kelly & Field 1996; S. Williams 2000a). Toombs, arguing from the perspective of a philosopher living with multiple sclerosis, calls for biomedicine to urgently and deliberately engage with hermeneutic perspectives, but nonetheless makes clear the biological reality of disease / illness:

For the chronically ill, disease is an intrinsic element of one's way of being, a permanent feature of living. Since the complete restoration of physical well-being is not a possibility, the chronically ill must learn to live with ongoing disorder – the goal being to live well in the presence of (rather than in the absence of) illness. The *emphasis, therefore, is not so much on confronting and vanquishing disease as it is on integrating illness and transformed bodily being into one's daily life* in a positive fashion (Toombs 1995:11 *Italics added*).

Despite agreeing with the criticism voiced by both Marks (2002) and Cornish (2004) (and implicitly with the critical realist critique) with respect to the BPSM's dualism and its lack of critical foundation, Borrell-Carrió *et al.* (2004) offer an altogether more positive interpretation of the BPSM and its impact on healthcare:

George Engel's most enduring contribution was to broaden the scope of the clinician's gaze. His biopsychosocial model was a call to change our way of understanding the patient and to expand the domain of medical knowledge to address the needs of each patient. It is perhaps the transformation of the way illness, suffering, and healing are viewed that may be Engel's most durable contribution (2004:581).

That said, Borell-Carrió *et al.* agree that, viewed from the perspective of 25 years of change, Engels' BPSM is in need of modification. They agree that there is a need to

abandon the dualistic model of mind-body, and argue that a recognition of knowledge as ‘socially constructed’ serves to facilitate this move (2004:581). Secondly they propose that what they term the reductive ‘linear model’ of causality should be abandoned for a model which recognises that medical diagnoses are made in open systems (2004:578; 581). In addition, they assert that the biopsychosocial model should develop a ‘relationship-centred care’ rather than a ‘patient-centred care’ perspective, and acknowledge the need to introduce the causal power of language into the model. Borell-Carrió *et al.* further argue that the development of ‘mindfulness’ (‘the habits of attentive observation, critical curiosity, informed flexibility, and presence — underlies the physician’s ability to self-monitor, be vigilant, and respond with compassion’) as necessary for the fulfilment of the ‘ethical mandate’ of the healthcare professional (2004:580). This understanding of mindfulness is congruent with the understanding of the central role of ‘reflexivity’ in Margaret Archer’s social realism (1995; 2000; 2002; 2003 – and below 2.3.3 – 2.3.5).

The ‘relationship model’ still requires further qualification. The relationship that is the focus here must be quite specifically the professional relationship that exists between the healthcare practitioner and the person seeking assistance. It is not merely a matter of ‘feel good’, but a *moral* relationship (Thomasama 1983; Borell-Carrió *et al.* 2004). While Thomasama rejects the term because of its religious connotations, Hepler’s (1987:376) recommendation of a ‘covenantal relationship’ is useful. Despite its religious connotations (at least in Western traditions), it points to the two-sided nature of any professional relationship: the professional and the person seeking assistance (6.2.3 below). Whereas the biomedical model and the ‘patient-centred’ model both focus on modifying the *patient*’s actions, the relationship model focuses on all parties involved in the process (including caregivers - Pilnick 1998). The relationship model also balances the over-emphasis on patient autonomy³ present in the patient-centred models (Thomasama 1983; Borell-Carrió *et al.* 2004) by recognizing the social context in which agency is exercised, and by recognizing that at times in the medical setting others must represent the patient (for example in the case of children or in cases where the condition of the sick person has limited their autonomy).

Understood in this way a biopsychosocial perspective potentially provides a useful theoretical perspective to inform a relationship-centred healthcare practice. As a way of

³ Understood as the capacity and exercise of authenticity and independence of decision making (Thomasama 1983:244, following Dworkin 1976)

distinguishing between the traditional BPSM and the approach to practice proposed by Borell-Carrió *et al.*, I suggest the use of an anagram derived from the description of practice they propose: ‘*biopsychosocially oriented clinical practice*’ (2004:579): the traditional BPSM thus becomes **BioPsychoSocialPractice** (BPSP). The BPSP perspective is congruent with pharmaceutical care (6.2.3) and ‘concordance’ (the recently proposed approach to medicine-taking decisions, 5.2.4, below). The ontological and epistemological perspectives of critical realism and a socio-cultural knowing suggested below (2.3 & 3.1 respectively) may facilitate a shift toward a BPSP. The BPSP perspective is also congruent with the social theory of social realism (2.3.2 – 2.3.5 below).

The healthcare perspectives (and accompanying assumptions) discussed above have implications for practice and therefore for the interaction between practitioners and the people who seek their services. While these implications will be considered in more detail below (Chapters 4 – 8), Table 2-ii provides a broad overview of the connections between perspective and practice:

	Biomedical	BPSM (Biomedical)	BPSP (Relational)
Ideal Focus	Practitioner / disease / product centred	Patient centred	Relationship centred
Goal / purpose	Cure of disease / relief of symptoms	Cure of disease through treatment of patient	Optimal therapeutic response to health-related needs of sick person
Ontology	Positivist, dualist, reductive	Varies: Positivist / Pragmatic / weak-constructionist; dualistic	Varies: phenomenological / realist; holistic
Epistemology	Positivist; empiricist	Varies: predominately empiricist (Marks 2002 & Cornish 2004) / phenomenological	Varies: phenomenological / socio-cultural / social-constructionist
Ideology	Professional control	Professional direction	‘Covenantal’ (Hepler 1987/2000)
Construction of sick person	As ‘patient’; passive; lay;	As lay ‘patient’; recognizes form of agency;	As person experiencing illness; social agent and actor;
Medicine practice	Compliance under practitioner’s supervision and control	Adherence / therapeutic alliance under practitioner’s direction	Concordance; optimal medicine practice with practitioner’s advice and support

Table 2-ii: Healthcare perspectives and practice

To adequately challenge the hegemony of biomedicine without denying the importance of scientific activity (or the biological body), Cornish proposes that a dialogical perspective is needed rather than what he terms the ‘aggregative’ BPSM. Borell-Carrió *et al.* (2004) agree

that such a perspective can correct the outdated BPSM. While Cornish proposes a model built on Hegelian principles (Cornish 2004), I suggest a perspective built on critical realist ontology. Critical realism offers promise as a philosophical underlabourer clearing the way for our better understanding disease, chronic illness, and health sector management (S. Williams 2000a; Connelly 2000). It also offers a philosophical basis on which to respond to Traulsen and Bissell's call for 'an entirely different paradigm: one that emphasises a disease- and patient- oriented approach to pharmaceutical decision-making' (Traulsen & Bissell 2004: 111).

2.3 Critical realism – ontological perspective

'all science would be superfluous if the outward appearances and essences of things directly coincided' (Karl Marx in Bhaskar 1979:10)

Since the mid-1990s Roy Bhaskar's understanding of critical realism has begun to influence sociology in general (Harvey 2002), and the debate around disease, illness and health care in particular (Porter & Ryan 1996; S. Williams 2000a). Bhaskar argues for an ontological perspective that rejects reductionism and scientism, but nonetheless assumes a realist position (1978; 1979). This enables an understanding of science under which both natural and social science may operate, but emphasises the substantial differences in the subject matter, methods and methodology of each (Bhaskar 1978; 1979; 2002).

This opens up the possibility of arguments about the relationship between the social world, which is the product of human actions, and the natural world, which exists independently of them, or so it used to be said. In a world subject to the threat of global warming and profound ecological transformation as the product of human industrial activity [to which we might add issues of medical technology such as transplantation, gene therapy and cloning], we really do need a story which links the natural and the social (Byrne 2002: 17 – 18).

Simon Williams (2000a) proposes that critical realism provides just such 'a story' as a basis for understanding healthcare practice in an integrated, non-dualist way. Noting the growing frustration and fragmentation within the sociology of health and illness, especially with regard to understanding the body, Williams reflects on how:

The body...is everywhere and nowhere today: the more it is talked about and studied, the more elusive it becomes....At best this has served to capture the multifaceted nature of the body in society. At worst it has led to a fragmentation of perspectives and a dispersal of approaches which, for the most part, continue to talk past rather than to each other....Critical realism, I venture, with its commitment to deep underlying structures and mind-independent generative mechanisms, offers us a promising way out of these dilemmas,

bringing the biological body back in, so to speak, without stripping agency of agency or structure of structure (2000a: 798).

2.3.1 The critical realist ‘story’ – the possibility of science

What then is the critical realist ‘story’? Critical realism rejects notions that the appearance of things corresponds directly with the way things are. Central to critical realism is the understanding of ontological depth, that is the recognition of reality as stratified. Critical realism argues for three domains of reality: the **real** (which is *intransitive*, consisting of objects and their structures, powers and liabilities, and generative mechanisms) which is greater than the **actual** (i.e. activities or the pattern of events that occur when the powers and mechanisms are activated and produce change), which is itself greater than the **empirical** (which consists of the phenomena we sense) (Bhaskar 1978; 1979; 1994; 2002; Fairclough, Jessop & Sayer 2002). The actual and the empirical make up the *transitive* dimension of reality (Bhaskar 1978; 1979; 2002). An important caveat within critical realism is the rejection of reduction to the lowest level as permitting an explanation of an object or event. Each stratum is **emergent** because while it ‘is the product of the reproductive mechanisms’ which make up the deeper strata, each cannot be reduced to the more basic strata and its powers and structures (Harvey 2002:165). ‘Shallower’ strata can, however, affect deeper strata. For example in the case of rheumatoid arthritis there are strong but not necessary links between physical injury (at the level of the empirical) and the autoimmune responses, until then unrealised. These autoimmune responses appear to exist (at the level of the real) in around one percent of the population (Lee & Weinblatt 2001). These responses in turn produce other events, at both the actual and the empirical strata, which have collectively been labelled as rheumatoid arthritis.

Critical realists argue that positivists (and empiricists) conflate the epistemological and ontological and mistake ‘the experience of constant conjunctions of events for the causal mechanisms that underpin them’ (Scott 2000: 14). Constant conjunctions may occur in the closed system of a controlled experiment, but are rarely – if ever – to be found in the open system of the world. This is well illustrated by Hampton (2002) in his comparison between clinical trials that inform ‘evidence based medicine’ and what he terms ‘real world’ medicine:

Clinical trials often include patients within a certain age group and with certain clinical characteristics; in the real world, patients are less well defined and do not fit the inclusion and exclusion criteria of the trial. In order to obtain “clean” answers, trials usually attempt to include only patients with a single disease; in practice, patients

frequently have multiple problems involving multiple therapies. Clinical trials, by their nature, tend to include low-risk patients, and when registers are maintained of all the patients who might have been considered for inclusion in the trial it is clear that the trial's results apply only to a very small proportion of the generality of patients....Clinical trials are a blunt instrument that only address simple questions. They can indicate whether a drug is effective treatment for a particular disease, but it is extremely difficult to design a trial of a total management strategy. Individual patients vary so much, and have so many different medical, psychological, and social problems, that one management strategy is unlikely to be effective for all those who happen to have one disease in common. In the real world of the individual patient, the practice of evidence-based (or even opinion-based) medicine is extremely difficult (2002: 562 – 563, 564).

Experiments serve not to 'discover' empirical regularities (these can be produced anytime), but to search for the 'causal complex, a process which will work independently of the closure' which lies beneath the observable phenomena (Bhaskar 2002:7). The scientist is thus looking for something that happens behind and beneath the observable events, and independent of human action – at the level of what Bhaskar calls the *intransitive* objects of inquiry (Bhaskar 1978; 1979; 2002). In open systems (i.e. in the world) these processes work alongside other mechanisms and agencies as co-determinants. Thus Humean 'causal laws,' which at best can only be expected to operate in closed systems, can now only be seen as *tendencies* which refer only to the activity of the causal mechanisms and not to their necessary outcome in open systems. Laws (understood as tendencies) can still be used to explain activities in open systems, but here they are 'deductively justified predictions' (Bhaskar 1979:13) and no more. There is thus an ontological difference between 'causal laws and their empirical grounds' (Bhaskar 1979:14).

The objects of scientific experimental activity are 'structured and intransitive, that is irreducible to patterns of events and active independently of their identification by men [sic]...the discovered exists independently of its discovery...[and]... in the transitive dimension... is not known prior to its discovery' (Bhaskar 1979:14 – 15). The fact that objects exist independently of our knowing of them does not mean that they are unknowable. However, 'work' (in the sense of production) is required to reach beneath the obvious and uncover the deeper strata (Benton & Craib 2001). As Archer notes:

Contra empiricism, experience is not passively imprinted on the senses by nature as if on a blank page. For both realism and phenomenology, we are thrown into the real world and make what we

can of situations, of which we have no prior understanding, through exercising our species' endowment in praxis (2000:127).

The essence of science in the critical realist view is thus that of 'the movement at any one level from knowledge of manifest phenomena to knowledge of the structures that generate them' (Bhaskar 1979:17). Scientific activity is the ongoing dialectical process of trying to unfold deeper levels / strata of reality beginning with a description of phenomena, which leads to theory construction using metaphor and analogy to explain 'generative mechanisms' which appear to be at work. The explanation then becomes the focus for further theory construction, and so on (Bhaskar 1979:15; 2002). Scientists, however, do not create theory / knowledge out of nothing, they must depend on ideas, concepts and models which pre-existed their specific experimental activity. Our knowing of pre-existing objects is thus necessarily socially and historically situated – knowing is a 'geo-historically specific social process' and is *transitive* (Bhaskar 2002:211).

Thus far we have noted two key elements of critical realism: ontological realism and acceptance of epistemological relativism; but there is a third element which Bhaskar terms *judgemental rationalism* (Bhaskar 1979; 2002). Recognising that knowing is a social process in which what was thought to be an accurate representation is often replaced by another, perhaps very different representation, does not necessarily lead to absolute relativism. There remain better or worse grounds for accepting a theory. Bhaskar illustrates this using Hume's statement that he could not 'give grounds' for leaving a room by the door rather than by the second story window. As Bhaskar notes, Hume never did leave by the second story window because he knew what would happen if he did. He acted according to judgemental rationalism, preferring the good grounds for accepting the argument for leaving by the door than the argument for leaving by the window (Bhaskar 2002). The concept of judgemental rationalism is important for this study as it has implications for our responding to all of life, including issues of health and illness. As Bhaskar explains:

[W]e cannot avoid what I have called the axiological imperative, that is we have to act and the action is not determined. We do actually have a free will, we do have a choice, however circumscribed it is by structural and other determinations, we have no alternative but to act and we need to know what are better or worse grounds for our action. So not to provide a criterion for those grounds is very serious because it means that anything we say [and do] becomes more or less arbitrary (2002:215).

An important application of judgemental rationalism would be the basis for accepting the existence of something. Science uses two criteria for accepting the existence of an entity, the empirical and the causal. In the case of the latter, the existence of something is accepted if the entity is able to bring about changes in material things: ‘On this criterion, to be is to be able to do’ (Bhaskar 1979:16). Science then does not depend on empiricist ontology and, argues Bhaskar, empiricist (and indeed idealist) assumptions about the social world are thus inadequate (Bhaskar 1979; 2002).

In Figure 2-1 below I provide a graphical summary of the essential elements of critical realism discussed this far, using Rheumatoid Arthritis as a reminder that there are real implications for taking philosophical positions and making decisions about knowledge choices.

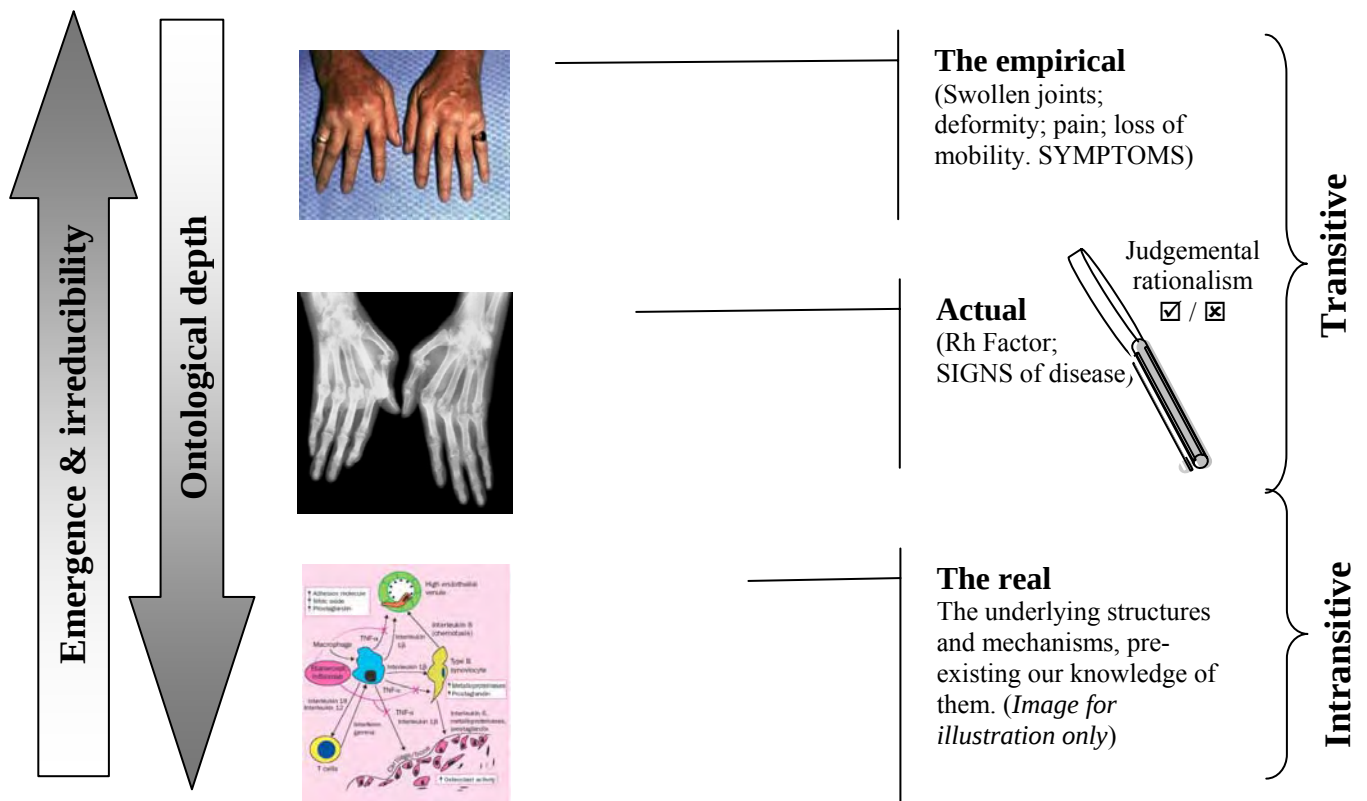


Figure 2-1: Critical Realist analytic view of RA (Illustrations, respectively, from Science Museum; Surgical Tutor; Lee & Weinblatt 2001:906)

2.3.2 The critical realist ‘story’ – the possibility of social science

Just as Bhaskar began his interrogation of natural science by turning Kant’s epistemological transcendental question into an ontological question, so he employed a similar strategy for his interrogation of the social sciences: ‘...what properties do societies and people possess that might make them possible objects of knowledge for us?’ (Bhaskar

1979:17 *Italics in original*). His response began by proposing that in their reaction to positivism, and to distance themselves from Humean causality and its attendant reductionism, the interpretivist schools in all their forms have defined themselves against and therefore carried over, albeit implicitly, a flawed ontological position: the ‘ontology of experience, *empirical realism*, and a sociology of man, *sociological individualism*’ (Bhaskar 1979:25 *Italics in the original*). Even those who deny that ontology is a legitimate project by arguing that the real is unknowable, commit the epistemic fallacy of collapsing ontology and epistemology (Bhaskar 1979; 2002; Archer 2000; Scott 2000).

The social sciences have been dominated by the hermeneutic imperative of seeking meaning and ‘conceptual connections’, an undertaking very different from the positivist-dominated natural sciences’ search for Humean law-like ‘constant conjunctions’ (Bhaskar 1979:22). Where the two opposing camps have met they have had little to say to each other, with naturalist approaches to the humanities ending up with reductionism and behaviourism. Bhaskar, however, argues that they have had two common understandings which are rooted in the flawed understanding of positivism noted previously: ‘Neither party doubts for a moment that empirical invariances are necessary for laws [which are anathema to hermeneutics], or that the conceptual and the empirical exhaust the real’ (Bhaskar 1979:22).

Critical realism argues against both of these assumptions by insisting that:

- causal laws are ‘deductively justified predictions’ (Bhaskar 1979:13) and express tendencies not constant conjunctions, and
- there is an essential metaphysical element to the real (the notion of powers and structures and emergent strata) (Bhaskar 1979; Archer 1995).

As Bhaskar comments, illustrating critical realism’s significance for this study:

From this [critical realist] perspective, then, things are viewed as individuals possessing powers (*and as agents as well as patients*). And actions are the realization of their potentialities. Historical things are structured and differentiated (more or less unique) ensembles of tendencies, liabilities, and powers; and historical events are transformations (Bhaskar 1979:24 *Italics added*).

Critical realism argues that there are causal tendencies at work in the social sciences and that these may be implicit and unexamined, and may be realised or unrealised, but these are tendencies and not reductive ‘empirical regularities’. A critical realist perspective

affirms that we are biological beings with a material element and so ‘deductively justified predictions’ or causal tendencies (as distinct from empirical regularities) must be recognised. This is one of the reasons why Simon Williams (2000a) argues that critical realism helps bring the body back into conversations about the sociology of health and illness. However, human beings possess emergent properties and so cannot be reduced to the biological, chemical or physical (Archer 2000; 2002; Bhaskar 2002). Social objects cannot be reduced to natural objects and cannot be studied in the same way as natural objects. Indeed the very nature of the social implies an always open system, making the closed system experimentation of the natural sciences ‘literally useless’ (Bhaskar 1979:27). This has the important consequence that at the level of the empirical, the social sciences ‘*cannot be predictive* and so must be *exclusively explanatory*’ (Bhaskar 1979:27 *Italics in original*).

It is, however, ‘only at the superficial level, of the analysis of laws as empirical invariances... [that the]...apparent symmetry between explanation and prediction in the natural sciences has no analogue’ in the social sciences (Bhaskar 2002:18 - 19). The judgemental rationality of social science is based on its ability to offer a better explanation (Bhaskar 1979; 2002). Predictive usefulness in social science is not based on empirical invariance, but on the adequacy of an explanation. For example, in a comprehensive review of research on patient medicine-taking behaviour, Vermeire, Hearnshaw, Van Royen and Denekens (2001) note that while a number of factors appear to impact on whether or not patients adhere to recommended treatment regimens, patients often explained that the complexity of the regimen (number of medications, frequency of dosage, length of treatment) was a prime reason for low adherence. It is, therefore, reasonable to use the explanations that are offered in the research to predict low adherence with complex regimens and to suggest that less complex regimens may be more effective in promoting adherence (assuming that the concept of ‘adherence’ is accepted — see Chapter 5 below).

2.3.3 Understanding the society/person connection

Reaching an understanding of the relationship between society and person (more commonly, *structure* and *agency*) bedevils sociology in general and in particular the sociologies of health and illness, and education (Tang & Anderson 1999; Willmott 1999; Archer 2000; 2003; S. Williams 2000a). Archer reflects that social theorists agree on very little regarding structure and agency, but hazards three grudging concessions that would be generally accepted with regard the influence of structure on agency: (1) That early ideas of

social determinism have been rejected; (2) there is ‘slim’ agreement that ‘in *some* sense ‘structure’ is objective...’; and (3), a similar tenuous acceptance that there is some element of the subjective with regard to agency (Archer 2003:1 *Italics in original*).

While traditionally in sociology ‘structure’ has referred to ‘any recurring patterns of social behaviour’ (Marshall, *Dictionary of Sociology*), social realism’s rejection of empiricism leads to a significantly different understanding. In a critical (or social) realist approach, structure is understood as ‘a set of internally related elements whose causal powers, when combined, are emergent from those of their constituents’ (Sayer 2000:14). *Social structure* is thus understood as ‘the aggregative consequences of prior [person-person/person-world] interactions’ (Archer 1982:468). These ‘aggregative consequences’ are emergent from social relations and social structure is therefore ‘*quintessentially relational* but none the less real because of its emergent properties which effect agents who act within it and thus cannot be reduced to their activities’ (Archer 1995:106 *Italics in original*). In critical / social realism *agency* (used in the plural) refers to the emergent property we have as humans to either re-form (i.e. actively/passively maintain) or transform the life-chances which we share with others (Archer 2000). Critical/social realism understands social agency (to be considered again in 2.3.4 – 2.3.5 below) as analytically stratified:

- *Primary Agent* (our conditioned involuntary membership of the collectivities to which we belong ‘without our compliance, consent or complicity’ by virtue of the life chances at our disposal constrained by our access to scarce resources) (Archer 2000:262);
- *Corporate Agent* (characterised by organisation and purposiveness, emerges ‘at the point at which agency succeeds in challenging and transforming the [socio-cultural] context’ in which the agent was pre-placed) (Archer 2000:268);
- *Social Actor* (emerges when we creatively occupy a social role) (Archer 2000; 2002).

Earlier sociological approaches have sought to maintain a structure-agency connection and separation. Berger’s dialectical model, and more recently Giddens’ structuration theory, provide two attempts to conceptualize the relationship between persons and society (Harvey 2002). While offering new insights these have each proven problematic. The dialectical model (Figure 2-2) argues that society is not independent of the human activity that

produces it, but once it does exist, society is coercive and resistant to the wishes of the individual human (the agent).

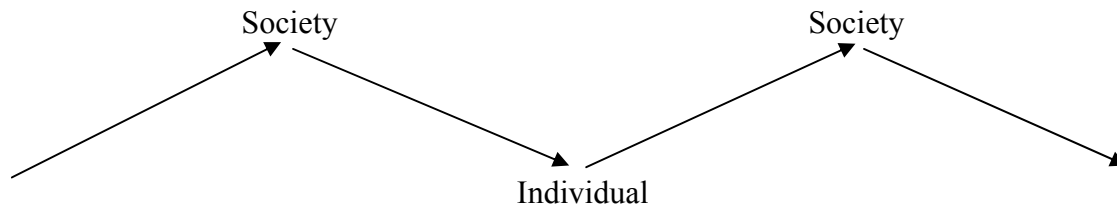


Figure 2-2: Berger's Dialectical Model (Bhaskar 1979: 40)

In this model society creates the individual *and* the individual creates society (Harvey 2002). Society is an objectification of man / woman in the sense that the individual is able to stand back from what her / his activity has produced and make the product (society) 'an object of his consciousness', but the individual is the internalization of society (Bhaskar 1979:41). Bhaskar represents this model as an '*Illicit identification of opposites*' leading to both voluntarism with respect to society, and determinism with respect to the individual (Harvey 2002:168; Bhaskar 1979:40).

With respect to structuration (crudely, structure + agency in action) theory, Willmott (1999) and Archer (2000; 2002; 2003) argue that Giddens, while clearly giving recognition to real human agency and challenging the dualism between society and individual, does so through the denial of the 'autonomy, priority, and causal efficacy of natural relations' (Archer 2000:22) and at the expense of committing a form of epistemic fallacy (Benton and Craib 2001), by collapsing structure into agency resulting in 'one indissoluble amalgam' in the form of the realm of human activity (Willmott 1999:6). Although Gareth Williams appears to suggest a favourable appreciation for structuration theory as a way out of the epidemiological tendency to ignore the impact of structure on agency (G. Williams 2003), at the same time he argues for the need to rediscover the individual narrative, the agent, in sociology of health and illness. A critical realist approach to the relationship between structure and agency appears to offer a way to retain both structure *and* agency without conflation, and it is to this I now turn.

Archer's (1982; 1995; 2000; 2002; 2003) sociological perspective (*morphogenesis*⁴) provides a far more thoroughgoing and nuanced presentation of a critical realist understanding of both structure and agency than that of Bhaskar (1979). In essence, as the term 'morphogenesis' suggests, Archer argues for an inter-relationship in which 'structure conditions agency, and agency, in turn, elaborates upon the structure which it confronts. Morphogenesis works by employing analytical dualism to 'delineate cycles of structural conditioning, social interaction and structural elaboration over time...' (2000:306). This approach differs from Berger's (essentially) linear dialectical model in that its conception is dialogical and cyclical, and so maintains *both* the inter-relatedness and differentiation of agent (subject) and structure (object), each irreducible to the other and each possessing emergent properties proper to themselves (Archer 2000; 2003).

Structure serves to enable or constrain, but *not* to determine human action (i.e. projects) (Archer 1995; 2003; Lewis 2000). This applies just as much where the enablement or constraint occurs without the agent's awareness and in circumstances where life chances have placed people differently so that 'opportunity costs' are different for each person. The varied opportunity costs do not provide a structural determination of a person's actions, but rather may increase the cost to one person over another. However, the agent still makes the choice as to whether or not that cost is worth it (Archer 2003). For example if a person is diagnosed with an illness for which there is no 'cure', but there is treatment available that may, at considerable potential costs (i.e. with significant side effects and perhaps life-style changes and economic implications) extend a greater possibility of life, such a person has to make the choices involved in opting for or against that treatment (unless overdetermined such as when a person is comatose and family members or the State may decide for the person). There is in fact no guarantee as to what choice any given person will make, thus recognising the fact that neither life-chances (disease) nor structure (particular family; society, medical profession, insurers, the state) can determine that person's decision. They may enable (granting social and material approval) or constrain (restrict treatment options; withholding approval – for example in stem-cell research or euthanasia – or withholding resources), but they cannot determine the person's choice unless, again, in a case of a comatose person and so on.

⁴ Archer borrows the term from Walter Buckley, *Sociology and Modern Systems Theory*, 1967: 'Morphogenesis refers to "those processes which tend to elaborate or change a system's given form or state" (p.58). It is contrasted to morphostasis which refers to those processes in a complex system that tend to preserve the above unchanged' (Archer 1995:75 n.11).

2.3.4 Reflexivity

Archer reminds us that constraints and enablements are not themselves entities and are therefore unlike natural scientific ‘... “inhibitors”, “catalysts” and “retarding agents”...’ which – unlike social agents – lack *reflexivity* (Archer 2003:6). Constraints and enablements are instead ‘potential *causal powers* of structural emergent properties’ (Archer 2003:5 *Italics in original*). These may remain unexercised unless an agent or agents engage in a project to which the emergent causal powers of enablement and constraint may relate. Simply put, while structure may be ‘*temporarily prior*’ and ‘*relatively autonomous*’ to a person’s decision to act (including inaction), if a person does not act (engage in some project) then there is no action upon which structural emergent properties of enablement or constraint may act (Archer 2003:14 *Italics in original*). ‘The effect of these structural and cultural causal powers [to constrain and/or enable] is at the mercy of two open systems; the world and its contingencies and human agency’s reflexive acuity, creativity and capacity for commitment’ (Archer 2003:7).

The possession of reflexivity is central to a person’s ability to deny structural determinism, and reminds us of the critical realist understanding of causality (especially in the open systems of the social world) as rooted in tendencies, not constant conjunctions of events (Bhaskar 1979; 2002; Archer 2000; 2003). *Reflexivity* is understood to be the practice of the *internal dialogue* through and in which we go about formulating a thought, ‘questioning ourselves, clarifying our beliefs and inclinations, diagnosing our situations, deliberating about our concerns and defining our own projects’ (Archer 2003:103). It is the process of ‘making up our minds’ in the sense that we ‘produce self-knowledge....internally and dialogically; it is not something we *discover* “lying inside us”’ (Archer 2003:103 *Italics in original*).

Reflexivity is thus central to human agency and its relation with structure, in other words to the mediation between structure and agency. Indeed, if we were not reflexive beings there could be no society, whether it consisted of two or two billion, because if we do not ‘know ourselves to be ourselves’ we could not know the other, nor could we know that anything refers to us (Archer 2003:19). Archer argues that while human intelligence, embodiment, reflexivity and openness to social influence are frequently taken-for-granted, once we recognise that:

...someone who knows herself to be herself [and] also knows that she inhabits her own body and, in so doing, she knows a good deal about

it, some of which will be known to her alone [then we have recognised] ‘private knowledge’. Next, a reflexive being, who is also an intelligent being, has the capacity to ask herself, how do other things, including people, affect me? The combination of reflexivity and intelligence has produced someone who can reflect upon the world. Already, reflexivity is no longer a discrete attribute, but a generative ability for internal deliberation upon external reality...Furthermore, this being, who now appears to engage in internal deliberations, is also held to be open to social influences....[and even if] a social influence can *itself* be immune to what people think about it...what they make of it reflexively can profoundly influence what they do about it (2003:19 - 20).

Reflexivity as a first-person⁵ generative ability for a person’s internal deliberation upon external reality (including situations not of our making or choosing) including both people and the social, that can profoundly influence what s/he does about that reality, including social structures, becomes fundamental for understanding human agency. So understood reflexivity has both individual (‘we can modify ourselves by reflecting upon what we most care about’) and social causal powers (‘as incumbents of [social] roles, actors need their reflexivity to know that the associated duties belong to them, themselves’) (Archer 2003:41). It is important to qualify the project of self knowledge and making of ourselves in that we do not make ourselves ‘under the circumstances of our own choosing’ – but always in the world, embodied (Archer 2003:104). Reflexivity thus has real significance for this study, as both the professional actions of the pharmacist and the actions of the (conscious) patient depend upon their reflexivity.

2.3.5 Agency, identity and reflexivity

Archer situates the social realist perspective on agency in the context of a detailed account of the wider sociological debate with respect to agency. This debate has ranged from the one extreme of an Enlightenment perspective (‘Modernity’s Man’ – Archer 2000; 2002) which argues for a vision on humanity (in the main, ‘man’) who stands independent of society, and for whom ‘relations with other beings...are merely contingent accretions, detachable from his essence’ (Archer 2002:11), to the other extreme of postmodernisms’ ‘Society’s Being’. Contrary to the under-socialized *Modernity’s Man*, the over-socialized *Society’s Being* ‘presents all our human properties and powers, beyond our biological constitution, as the gift of society’ (Archer 2002:12).

⁵ Archer’s argument for reflexivity as a first-person act is argued at length throughout *Structure, Agency and the Internal Conversation* (2003), but especially pp.19 - 52.

Archer begins with a critique of both *Modernity's Man* and *Society's Being* that is thoroughly detailed in *Being Human: The problem of Agency* (2000), but perhaps is captured in essence in her assertion that:

From the realist point of view, the central deficiency of these two models is their basic denial that *the nature of reality* as a whole makes any difference to the people that we become, or even to our becoming people....What is lost, in both versions, is the crucial notion of experience of reality; that the way the world is can affect how we are. This is because both anthropocentrism and sociocentrism [*sic*] are two versions of the 'epistemic fallacy', where what reality is taken to be, courtesy of our instrumental rationality or social discourse, is substituted for what the world really is. Realism can never endorse the 'epistemic fallacy' and, in this connection, it must necessarily insist that how the world is has a regulatory effect upon what we make of it and, in turn, what it makes of us (2002:12).

Of particular relevance to this study is Archer's distinction – contra social constructionists – between the prior *sense of self* (which grows out of relations between humanity and the world) and the social *concept of self* (2000; 2002). Archer argues that 'our continuous sense of self is ... ontologically inviolable [while] our personal and social identities are epistemologically vulnerable' (2000:2). Our sense of self – growing out of our embodied experience of the world – cannot be reduced to a social construction as it is pre-social, pre-linguistic in its origins if not in its maintenance. A *sense of self* emerges from our embodied experience of and in reality, our 'embodied practices in the world' which are necessarily prior to any social relations – including language (Archer 2000:121). This understanding is supported by Gee's emphasis on the distinction between 'language' and 'meaning', in which he notes that we 'learn to mean' before we 'have begun the process of language acquisition in earnest' (Gee 1990:73).

Our embodied *sense of self* enables the distinction between self and not-self, something which must necessarily be prior to the ability to construe⁶ the social (Archer 2000; 2003). For a *concept of self* (to which are related our personal and social identities) to develop a person would need to have some form of *continuous sense of self* (or *self-consciousness*) to

⁶ I understand the usage of 'to *construe*' with respect to the social world, in the sense of '...to interpret the meaning of...to discover by inference; deduce' (Collins English Dictionary 1997) and 'to *construct*' as 'to put together substances or parts, esp. systematically, in order to make or build...something formulated or built systematically...a complex idea resulting from a synthesis of simpler ideas' (Collins English Dictionary 1997). The latter is implicit in 'social constructionism' against which Bhaskar (1979; 2002), Archer (1995, 2002, 2003) and Sayer (1992; 2000) argue (2.3.1 – 2.3.3 above).

be able to recognise that social expectations forming such a concept have a direct impact on her / him ‘rather than just being diffuse expectations’ (Archer 2000:7). The existence of *self-consciousness* – emergent in our embodiment and prior to our social experience – is vital to any significant understanding of reflexivity, because reflexivity is rooted in our ‘ultimate concerns and commitments’ (Archer 2000:2). If these latter are merely discursive constructs, gifts of society without root in a *continuous sense of self*, then they are ephemeral and we are (oxymoronically) rendered ‘passive actors’ – ironically reflecting the ideologically loaded medical view of the ill person, a ‘patient’ constructed by society.

Self-consciousness develops and is maintained in *practice* (of which language is but *an* example), and so ‘very young children’ will lack reflexive capacity (Archer 2003:39). The continuous nature of self-consciousness rests within our memories (following Merleau-Ponty in Archer 2000:8). Against the argument that memory is fallible and incomplete, Archer points out that a complete memory would in fact incapacitate us: ‘total recall is not what we should expect to find in the non-pathological human being’, rather it is in the ‘durable powers of recognition, our lasting and distinctive eidetic memories and the indelibility [unless overdetermined] of our performative skills... [which]...are sufficient to supply a continuous sense of self’ (Archer 2000:8). It is in this sense of knowing oneself to be the same over time that reflexivity rests (in non-pathological human beings, and clearly this would exclude people evidencing Korsakov’s Syndrome or Alzheimer’s, for example).

Out of our *continuous sense of self* emerges our *personal identity* (Archer 2000; 2002). *Personal identity* is the result of our reflexive engagement with the world (the natural, practical and social orders), during which we make decisions (often compromises) about where our priorities will lie and which order we will prioritise, viz. personal safety, performative achievement, or social worth respectively (for example, in a decisions as to whether I will accept a dare to bungee-jump or not). Out of these constant reflexive decisions at the interface between agency and structure, our *personal identity* emerges and is maintained/developed over time (Archer 2000; 2002). ‘Fundamentally, *personal identity* is a matter of what we care about in the world’ (Archer 2002:15 *Italics original*).

Directly related to the emergence of our *personal identity* is Archer’s understanding of emotions and their role in human agency. This is of specific significance to the argument of this study that attention to the affective domain is vital for the educational preparation of

pharmacy students to support people living with chronic illness (see 7.3 below). Archer argues that it is out of and within the very problem of having to deal with the simultaneous demands on our person of the natural (e.g. safety), practical (e.g. performative achievement) and social or discursive (e.g. concerns of self-worth) orders of life, that our emotions emerge (2000; 2002).

Our emotions serve to ‘convey the import of different kinds of situations to us’; emotions are what Archer terms ‘commentaries on our concerns’ (Archer 2002:16). So for example, a teenage would-be fire-walker at a religious ceremony may experience the emotion of ‘fear’ when faced with the bed of glowing coals (at the level of the natural order, he knows fire will hurt), but having prepared himself (spiritually and psychologically) and attended to the experience of others to ‘walk lightly’ and not run thus digging up the coals, he is caught up in the emotion of euphoria of the moment and is sure (at the practical order level) that he can do this, and (at the level of the social order) he is acutely aware of the eyes of his community upon him and that both his and his family’s reputation is at stake. So despite his fear, he prioritises the social (the emotion of worth versus shame) over the natural and walks across the coals. How that experience ends could have a substantial impact on how he prioritises those orders in the future (Archer 2002). The problem of humanity thus lies in the need to deal with the emotional commentary with respect to all ‘three orders of reality’ at the same time (Archer 2002:16). Our *personal identity* emerges in the way each person works out a way to live (Archer’s ‘*modus vivendi*’ – 2002:16) by developing a more-or-less stable balance between the demands of each of the orders of reality.

At the same time we are not entirely free to make of ourselves who/what we want. We are constrained by circumstances over which we have no necessary control, and it is in the social context in which we find ourselves that our *social identity* arises. Typical of realist perspectives, Archer reminds us that we cannot elide personal and social identity. *Personal identity* arises as we have noted, from our relations with all three orders (natural, practical and social), whereas our *social identity* emerges out of our social relationships (Archer 2000; 2002). Our *social identity* is thus a ‘sub-set’ of our *personal identity* (Archer 2003:120). Different persons will then assign different degrees of importance to self-worth and therefore invest differently in social roles. Archer argues for a dialectical relationship between our *personal* and *social identities* (2000; 2002). This relationship ‘culminates in a *synthesis such that both personal and social identities are emergent and distinct, although*

they contributed to one another's emergence and distinctiveness' (Archer 2002:18 Italics original).

What is important for this study is Archer's insight that *personal identity* is not 'swamped' by social identity, but does influence our (social) role selection, even if the roles available to us may include involuntary roles which we 'personify in a singular manner' (Archer 2002:18). I did not choose to be placed in the role of a 'heart transplant recipient', however the way I exercise that role will be different in singular ways from the way other heart transplant recipients will do so. At the same time, *social identity* does impact on personal identity in what Archer terms the second (analytical) moment of the synthesis (2000; 2002). Both voluntary and involuntary social roles impact on how we live out our personal identity. The way I choose to live as a transplant recipient (rigidly observing every dietary guideline, avoiding enclosed public spaces, wearing a protective face mask to help avoid viral infection) may prove to severely limit my social life, and so after a few months I may choose to relax or abandon certain or all of those role choices. At the level of my *personal identity*, I will have learnt that I am willing to compromise on natural order choices in order to make the decision to have a transplant worthwhile. However, Archer notes, at an objective level 'the opportunity costs' involved in my first choice have limited the second choice I make 'and corrected positions may be harder to come by' (Archer 2002:18). For example, relationships may have been strained or even lost because of the social restrictions involved in my first choice.

The synthesis, or third analytical moment in the dialectic arises once a person has found a role (or way of inhabiting a role) with which he or she is satisfied. The question then becomes one of 'how much of myself I am prepared to invest' in this role (Archer 2002:18). So as a 'patient' I now have to balance the demands of this role with other role demands: parent, spouse, career, and so on. What is significant here is that while involuntary roles such as those involved in illness, may severely constrain choices, choices nonetheless remain (again, except in extreme cases such as coma), and these choices are made by the person involved: 'The resultant [sic] is a personal identity *within which* the social identity has been assigned its place within the life of an individual' (Archer 2002:19). Our personal identities, whether as professional pharmacist or as patient living with chronic illness, are thus, unless overdetermined, not reducible to 'social gifts' (Archer 2000; 2002). It is this emergence of a person's capacity for transformation of the given (this includes

‘transformative negation of the given’ – Bhaskar 1994:92) that permits the embodied individual to challenge – and change – social roles, which may lead to emancipation. So the pharmacist may choose to challenge the prescription ordered by the doctor; the patient may choose to reject the advice of ‘doctor’s orders’, or even may choose to reject treatment in favour of briefer, less compromised, life.

In a nutshell, the individual, as presented here in his or her concrete singularity, has powers of ongoing reflexive monitoring of both self and society....[and]...is capable of authentic *creativity* which can transform ‘society’s conversation’ in a radical way... (Archer 2002:19).

Such an understanding of agency is powerful when considering health (Popay, Williams, Thomas & Gatrell 1998), chronic illness (including terminal stages) and disability. Being chronically ill, even being physically incapacitated and needing (and indeed wanting) help from healthcare professionals, and wanting such professionals to accept the burden of day-to-day praxis and decision-making, does not deny agency. A patient is and remains a personal agent irreducible to the biological, and illegitimately regarded as passive (S. Williams 2000a). At the same time, the biological body acts as a referent that ‘insists that what is the case places limits on how we can construe it’ (S. Williams 2000a:808). It is also powerful in considering the actions chosen by a pharmacist in deciding whether to risk challenging a perceived social role as subservient to the doctor by questioning a prescription she (professionally) regards as inappropriate for a particular patient, or by challenging the (increasing) de-professionalization of the pharmacist to shopkeeper, in order that she may act to offer professional support to a person using chronic medication. (See Chapter 6 for a discussion of the role of the pharmacist).

It is of course the exercise of this agency that presents healthcare with one of its most intractable challenges in the form of interactions around treatment of illness, and in particular, chronic illness: the decisions patients make with respect to treatment advice from healthcare practitioners. Most commonly in the literature this has been referred to in terms of *compliance* or *non-compliance*, terms which leave little space for patient-agency and to which I will return later (5.1.1 – 5.1.5 below). Over the past decade, increasing challenges to this understanding of the patient’s passive role have dominated the literature relating to patient care issues in the sociology of health and illness, health psychology, pharmacy and medicine (Vermeire, *et al.* 2001; Cox, Stevenson, Britten & Dundar 2002; Bissell, May & Noyce; 2004). The psychosocial response has tended to seek to understand

the patients' perspectives, challenge the power relations, and question the social structures, but in their ontological silence have 'left the body to biomedicine'. The patient-without-body has been left as an increasingly impaired, muffled protester, while the healthcare professional is without access to the patient-as-agent (Scherman & Löwhagen 2003). As Turner (1987), Frank (1995), Tang and Anderson (1999) and Simon Williams (2000a) argue, an understanding of agency which fully recognises the body is vital to developing an understanding of chronic illness 'rooted in real impaired bodies: bodies problematically 'written' both in and out of the picture by postmodernists and disability theorists alike' (S. Williams 2000a: 810 – 811).

Just as critical realism offers a new 'place to stand' with respect to understanding chronic illness and disability (S. Williams 2000a), so it offers a new perspective on chronic illness and the human (individual and social) praxis of medicine-taking. Like disability (to which in many cases it leads), chronic illness can be understood from a critical realist perspective as:

an *emergent* property, located, temporally speaking, in terms of the *interplay* between the biological reality of *physiological impairment*, *structural conditioning* (*i.e. enablements/constraints*), and *socio-cultural interaction/elaboration*. Within this model, structures may be faithfully reproduced or transformed through the conscious awareness and critical praxis of social agents, both individually and collectively....The social, in short, is more satisfactorily addressed (*i.e. no mere linguistic contrivance*), and the body/society relationship, in turn more adequately worked through (*i.e. both structural conditioning and degrees of agential freedom*)...(S. Williams 2000a:810 Italics in original).

2.3.6 Conclusion

The preceding sections have outlined the ontological and social theoretical perspectives that have direct bearing on this study. I have considered a social theoretical perspective of the human person as reflexive, self-knowing and capable of acting on that knowing, undetermined by social structure, yet whose projects are enabled or constrained by structure. This realist social theory is rooted in a critical realist ontology which holds that our knowing of an object does not correlate exactly with reality: epistemology and ontology are separate (Bhaskar 1978; 1979; 1994; 2002). Some indication of the epistemological perspective that will inform this study has been given in critical realism's assertion that knowing relates to the transitive, is geo-historical and socially constructed. It is to an outline of the epistemological perspective that informs this study that I now turn.

Chapter 3 : Shaping Perspectives (Cont' d): Epistemology and Risk

At one end is a team of epidemiologists fixed on cancer mortality and tumour detection rates as their end points. At the other end are individual patients and their advocates, padded with anecdotal evidence, determined to keep the locus of control within their own hands and bodies. Seen in this light, these 2 groups, while desirous of the same outcomes, are scarcely playing in the same match. Where and how do the locus of control and anecdotal evidence factor into cancer mortality rates? Should they?

Perhaps, at root, these are questions of epistemology — of what constitutes knowledge, and of the means of our knowing. Is the problem simply that patients and epidemiologists know, and want to know, different things? In the diagnosis of endometriosis¹ there has been a recent rapprochement between these means of knowing. The conventional definition based on histologic findings, which led to inflated prevalence rates, has been supplanted by one that includes the patient's experience of the disease (e.g., dysmenorrhea, pain and infertility) (Hoey 2002:157).

3.1 Introduction

Moving on from a consideration of the ontological and sociological perspectives, this chapter outlines the epistemological perspective which has shaped this study. The epistemological perspective presented here has been influenced by both Sayer (1992) and Wells' (1999) *sociocultural* understanding of knowing and knowledge. I then offer a brief consideration of the way the concept of the risk society (Beck 2000) may inform the *practice* of pharmacy.

'Practice' is emphasised here to call attention to the way *risk* forms links between (1), the commonsense usage of 'the exercise of a profession' (Collins Dictionary 1997), and (2), Archer's (1995; 2000; 2003) argument for the primacy of practice in human reflexivity and agency, and (3) Sayer's insistence that 'knowledge concerns not only "what is the case" or "knowing-that" but "know-how", that is knowing how to do something, whether it be physical behaviour or communicating successfully with someone' (Sayer 1992:14). So, living in a 'risk society', understood as living with unintended consequences (3.2 below), requires learning *how* to live reflexively, and thus becomes an epistemological issue.

Critical realism rejects positivist / empiricist assumptions about knowledge as presupposing 'both a conception of [persons] as passive and autonomized in experience

¹ 'Endometriosis' is medically described as the presence in other organs (such as the ovaries) of mucous membrane normally found in the uterus. This is experienced by the patient as often severe menstrual pain and infertility.

and a conception of the world as constituted by given and atomistic facts' (Bhaskar 1979:158). In the critical realist perspective, knowledge lies in the process of human praxis that is transitive, social, geo-historical, emergent and concerned with understanding the ever deeper stratification of the world (Bhaskar 2002). Knowledge is thus not an individual possession, nor even a social possession, but a relational process. It is this characteristic of knowledge that urges the need for a relationship-centred approach to healthcare, and especially to the process of therapeutic decision-making (including decisions by patients with respect to medicine-taking).

3.1.1 A sociocultural perspective

As with Bhaskar (1979) and Sayer (1992), Gordon Wells rejects the idea of knowledge as the possession of a given body of knowledge. Wells provides a carefully argued understanding of knowledge-as-process as underlabourer for a sociocultural² perspective and practice of education (Wells 1999).

A problem with any discussion of 'knowledge' is that the word is so imbued with its traditional meaning, while at the same time referring to concepts that range from discrete 'facts', through complex theories, skills and strategies, that it is difficult to develop new ways of 'meaning' knowledge. Instead Wells suggests that following a Vygotskyian-like 'genetic' approach (concerned with the genesis of human praxis) helps clear the field. Such an approach shifts the focus from outcomes or artefacts to human activity, knowing not knowledge (Wells 1999), a perspective which accords with critical realist perspectives (Bhaskar 1979; Sayer 1992) (Figure 3-1 below):

² From this point on I use the term 'sociocultural' to refer only to epistemology – to knowing. This is to try and distinguish such an understanding from 'social constructionist' which refers to a collapsed ontological/epistemological position. Unfortunately the terms social constructivist / social constructionist are frequently used interchangeably in much of the literature, often collapsing ontological and epistemological positions.

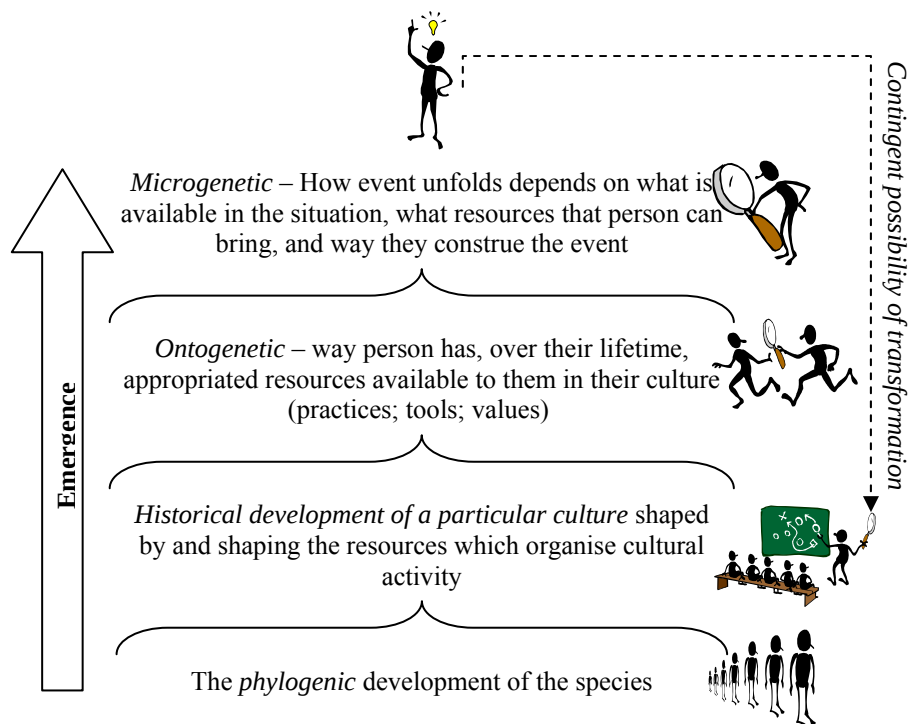


Figure 3-1: Graphical representation of Well's 'genetic' approach (based on Wells 1999: 55 - 56)

Each stratum (Figure 3-1) is emergent and cannot be reduced to the underlying stratum or strata, and each element operates over different time scales. As reflected in Figure 3-1, the more extended levels constrain and provide resources for the briefer, more recent or current levels. Equally since no event is exactly the same as a previous one (no constant conjunctions of events in open systems), each microgenetic level event involves transformation of the person, potentially also downwards-onwards (in history through time) to the more extended levels. Such transformation is contingent on the nature of the microgenetic level event and other unpredictable open-system influences, such as the status of the actor(s) and her/his/their power within the community. This perspective recognises the dialectical relationships that exist between 'continuity and change', while acknowledging the constraining nature of both the social and human embodiment, and their relationship with the individual located within socio-geo-history (Wells 1999). Archer's (2000:161 – 173) social realist description of the relationship between *embodied* knowledge ('knowing how' - knowledge involved in interacting with the world, lacking in cognitive awareness), *practical* knowledge (procedural, skills, implicit, tacit and gained through activity, 'extensive of our body', gained through apprenticeship), and *discursive* knowledge (propositional, the interplay between the corpus of a cultural system and the discursive relations between its human users) appears congruent with the phylogenetic, ontogenic and microgenetic strata in Wells' sociocultural model.

3.1.2 Modes of knowing

Wells argues that humans have developed six ‘modes of knowing’ over time. Each mode is associated with a particular function in social activity and each employs a distinctive artefact (Table 3-i). Each mode is characterised by emergence and so the most recent cannot be reduced to the earliest, nor can the earliest be regarded as inferior to the most recent:

Different modes of knowing make different functional contributions to an overall activity system; each is more appropriate for some tasks and conditions than for others and none is superior in all situations. They are complementary rather than in competition (Wells 1999:72).

History	Mode	Function in social activity	Artefact
2 million years	Instrumental	Individual in action (skilful use of an artefact as a tool; un-detachable from actual action)	<i>Primary artefacts</i> (material tools)
1 – 1.5 million years	Procedural	Between individuals while engaged in action (e.g. mimetic directions for hunting, making an arrow)	<i>Secondary artefacts</i> (tools & practices; social interaction)
50 000 years	Substantive	Among members of a cultural group, reflecting on action and as a basis for planning further action	<i>Secondary artefacts</i> (representations of tools & practices; spoken interaction)
50 000 years	Aesthetic	Among members of a cultural group, making sense of the human predicament (e.g. religion, art; poetry, drama, narrative, song, dance)	<i>Tertiary artefacts</i> (artistic representations in narrative; graphics; musical, etc., modes)
2 500 years	Theoretical	Among members of a specialist community, attempting to explain observations of [in order to control?] the natural and human world	<i>Tertiary artefacts</i> (decontextualized representations such as taxonomies, models, etc)
?	Meta	Among members of a cultural group, also by individuals seeking to understand and control their own mental activities	<i>Tertiary artefacts</i> (representations of mental and semiotic processes)

Table 3-i : Modes of Knowing (adapted from Wells 1999: 71)

It is not difficult to see how these modes of knowing could describe the healthcare professional / patient space, and offer the possibility of identifying where different commitments to ‘knowing’ predominate and, therefore, fail to connect with those using other modes. I shall consider this in more detail when I consider the concepts of ‘illness’ (in which for example, Aesthetic, Theoretical and Meta modes could be said to dominate) and ‘disease’ (in which the Instrumental, Procedural, Substantive and Theoretical modes might dominate).

Knowing as ‘the construction of *and use* of representational artifacts [*sic*]’ (Wells 1999:72 *Italics added*) makes use of an understanding of ‘representation’ that extends beyond a mere ‘mind as mirror’ and deliberately excludes identification of theory with reality. Wells argues that:

Representing is making or using something heuristically to “suggest how we would proceed in structuring our understanding of the world and of ourselves” [Wartofsky 1979].... From this perspective, representations are those artifacts that are used as mediational means for the related ends of understanding and acting effectively on the world. They become representations when so used (Wells 1999: 68).

This understanding of ‘representation’ is supported by Sayer’s critical realist argument that representation ‘provides means by which we can do things in the world or *cope* with events’ (Sayer 1992:59 *Italics original*).

While scientific models or frameworks are one form of artefact created deliberately for use as a representation, even material artefacts can (sometimes simultaneously) be both a tool and a representation. So a stethoscope draped around the neck of a wearer may well be placed there simply for ease of access, but it serves also to (re)present the ‘wearer’ as a medical professional. The stethoscope as a material object is a primary artefact of instrumental knowing (it ‘results from the transformation of a part of the environment for the purposes of successful production and reproduction of the means of existence’ – Wells 1999:69). It is a primary artefact of knowing only because it carries in itself some indication of its mode of production. In the procedural mode of knowing the stethoscope could be a secondary artefact (‘objects created for use in the purpose of preserving the skills and practices involved in the production and use of primary artefacts and of the transmitting of those skills and practices’ – Wells 1999:69). In this mode it could be used as a representation to provide instruction to others on how to use a stethoscope. However, it can also serve as a tertiary artefact in the aesthetic mode of knowing, for example as a symbol of medical authority distinguishing the bearer from a patient or visitor.

3.1.3 *Where is knowledge to be found?*

If knowing is ‘the construction of *and use* of representational artifacts [*sic*]’ involving both individual and society’, then where is knowledge situated? In responding to what he terms the question of the ‘ontological status’ of knowledge, Wells rejects the traditional tendency to locate knowledge in either the artefacts of modes of knowing (e.g. texts) or in something akin to Plato’s ‘timeless realm of pure ideas’ or Popper’s ‘World 3’ (Wells 1999:73). Such attempts tend to lead to reification of ‘knowledge’. Reification leads us to separating *a* representation from the *activity of* representation. Knowledge is representation and as such is ‘the current, but temporary, focus of the mental process of making or using some form or artifact *as* a representation of something else in an effort to understand.... knowledge...is simply what the activity of knowing is about or directed to’ (Wells

1999:75 Italics in original). Wells offers an understanding of knowing as:

the intentional activity of individuals who, as members of a community, make use of and produce representations in the collaborative attempt to better understand and transform their shared world (1999:76 Italics in original).

Understanding knowledge in this way makes sense of ideas of knowledge as ‘distributed’ over all elements of any action: ‘the participants, the mediating artifacts, the discourse and the situation’ (Wells 1999:75). Understanding what is happening thus involves the relationships (the structures and mechanisms) between all the elements involved (Wells 1999).

How then do we come to know? Wells links the concepts already noted (the modes of knowing and their artefacts) to what he terms a four-quadrant model based on ‘experience,’ ‘information,’ ‘knowledge-building’ and ‘understanding’ (1999:84) which he represents diagrammatically as (Figure 3-2):

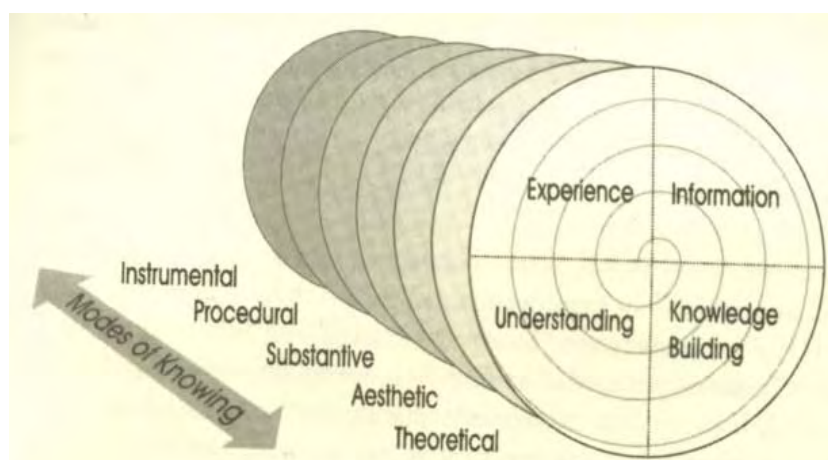


Figure 3-2: Wells' Spiral of knowing (Wells 1999:85)

The meaning of the terms on the Modes of Knowing axis have been presented. Wells specifically defines his usage of the terms on the horizontal and vertical axes as follows (Table 3-ii):

Experience	A person's 'culturally situated, affectively charged, participation in the multiple communities of practice that constitute his or her life-world...experience is not what happens to a person, but the meanings that are constructed in the course of participation in the succession of events that make up his or her life trajectory' as the person construes these events based on their conception of the world.
Information	Is second-hand, made of up of the experiences (as defined above) of others and encountered through a range of genres. Its value will be determined on how it is integrated into the person's experiential meaning, life and concept of the world.
Knowledge building	Also relates to meanings in the world, but how the person is engaged with others in making meaning, it is intentional, active and seeks a coherent construction, although 'temporarily detached from primary activity'.
Understanding	Understanding is 'more personal an immediate' than knowledge building, more holistic, intuitive and not necessarily made explicit, deeply involved in action, understanding creates possibilities for and constrains our actions – 'constitutes the interpretive framework in terms of which we make sense of new experience' and guides action.

Table 3-ii: Definitions of quadrant descriptors (Wells 1999:84 - 85)

We come to know, then, through personal experience (interpreted through our existing frame of reference or understanding), supplemented by information, intentionally extended and transformed through knowledge-building to become understanding (Wells 1999). However, as the 'Spiral of knowing' (Figure 3-2) demonstrates, these four dimensions also move along the Modes of Knowing axis, adding a third dimension of movement from instrumental to meta-knowing. It is clear from this model that knowledge-building and understanding require more than experience and information (which can be seen as arbitrary). What is required is not simply the exposure to experience and the transmission of information, but the *transformation* of the knowledge artefact (Wells 1999). This highlights the importance of the dialectical and processional relationship between the personal meanings of experience and understanding, and the social meanings of information and knowledge construction. Personal understanding can be facilitated through the social activity of knowledge-building (Wells 1999). Such a perspective is congruent with both a critical realist recognition of 'the key role of *practice* in learning processes' (Sayer 1992:52 *Italics original*), and a social realist understanding that 'experience is not passively imprinted on the senses by nature as if on a blank page. We are thrown into the real world and we make what we can of situations, of which we have no prior understanding, through exercising our species endowments in praxis' (Archer 2000:127). The movement from experience or acquisition of information to understanding involves access to socially mediated knowledge artefacts and to the knowledge-building community. It requires access to the values, attitudes and practices of the social community in which the knowing must occur (Wells 1999; Sayer 1992). It is this that links knowing and *discourse*.

Thus far I have considered, albeit briefly, two of those elements of an action over which knowing / knowledge is distributed: the *participants* (society and the individual) and the *mediating artefacts* (Table 3-i). To some extent I have raised the issue of the *situation* (the healthcare practitioner / patient space in chronic illness), although I shall return to examine this further. It is to *discourse*, the fourth element of an action, to which I now turn.

3.1.4 Discourse

Discourse is an essential (but not sufficient) element for knowing (Wells 1999). Discourse is also central to the substantial amount of literature and research that has grown around health care practitioner / patient interaction (Ainsworth-Vaughn 2001; Fleischman 2001; Boutain 1999). Of particular significance for this study, discourse is inseparable from any consideration of illness (Gwyn 2002). While I shall give more attention to discourse below (7.2.3 & Chapter 8 below), for now it is important to clarify my understanding of discourse, and to suggest how this understanding is congruent with critical realist and sociocultural perspectives.

The term ‘discourse’ is problematic as the term has a number of complementary and contradictory usages (Fairclough 1989; Gee 1990; Johnstone 2002). The term is used to refer to both (or either) ‘connected stretches of language that make sense’ (Gee 1990:142), and/or to:

systematically-organised sets of statements which give expression to the meanings and values of an institution [or community]. Beyond that, they define, describe and delimit what it is possible to say (and by extension – what is possible to do or not to do) with respect to the area of concern of that institution [or community] whether marginally or centrally. A discourse provides a set of possible statements about a given area and organises and gives structure to that manner in which a particular topic, object, process is to be talked about. In that it provides descriptions, rules, permissions and prohibitions of social and individual actions (Kress 1989:7).

Fairclough argues that the ambiguity in the usage of ‘discourse’ is felicitous because ‘it helps underline the social nature of discourse and practice by suggesting that the individual instance always implies social conventions...’ (Fairclough 1989:28). While this may be so, this ambiguity also easily translates into confusion. In order to reduce the confusion and distinguish between the two usages, I shall use ‘texts’ to refer to ‘connected stretches of language that make sense’ (Gee 1990:140), and ‘discourse’ to refer to ‘conventional ways

of talking [writing/reading] that both create and are created by conventional ways of thinking. These linked ways of talking and thinking constitute ideologies...and serve to circulate power in society' (Johnstone 2002:3). When referring to specific communities marked by, and using, particular discourses, I shall refer to these as 'discourse communities'.

Discourse, then, is a social process that is inherently a component of society (Fairclough 1989). Language is not only a process upon which society acts, but one which *acts upon* society, *effects* society (Fairclough 1989; Sayer 1992), indeed even 'the world of matter' (Archer 2000:157). *Discursive* practices are practices 'through which texts are *produced* (created) and *consumed* (received and interpreted)' (Philips & Jørgensen 2002:61). As such they are *in part* constitutive of the social world (Gee 1990; Philips & Jørgensen 2002; Chouliaraki 2002). For Bhaskar discourse is 'an efficacious mechanism which operates on the world and is embedded in the world, and [upon which] the world acts ...' (Bhaskar 2002: 89). Discourse is thus causal and real (Bhaskar 1979; 2002; Fairclough, Jessop & Sayer 2001), both a process and a product (Wells 1999), and is in part constitutive of and constituted by society (Archer 2000). This constitutive characteristic of discourse means that it is value-laden:

Specifically, discourse sets up a constitutive relationship between meaning and power within social practice: every move to signification comes about from a position of power – power both structuring and structured by the social positions available within a practice (Chouliaraki 2002: 83 – 84).

But as Johnstone observed (2002:3), discourse also refers to the 'conventional ways of talking...'. The reference to 'conventional' is a useful reminder of the 'ordinariness' with which 'ways of talking and thinking' are regarded, granting them unquestioned commonsense authority.

A person can be (and usually is) a member of a range of different discourse communities at the same time (Gee 1990). For example a student may be a member of a working class family, but being the first member to attend a university, she is also a member of the academic community (however peripherally). If she graduates with a Bachelor of Pharmacy degree and completes one year's internship, she becomes a member of the community of professionals called pharmacists, and arguably a member of the wider community of healthcare professionals. She also becomes a member of the local business community, and may tutor part-time in the local university's Pharmacy school. At no time

does membership of any one of these discourse communities necessarily mean that she ceases to be a member of another – although this may bring conflict (for example when she goes home and tells her father he must ensure that he takes his ‘hypertension medication’ rather than ‘the pills for his high blood’ – the latter reflective of typical South African working class accounts of hypertension).

How does an individual become a member of a discourse community? Gee argues that gaining access to a discourse community³ cannot occur through learning as a result of teaching, or even through reflection on experience. The only access a person has to a discourse community is through *acquisition*: ‘enculturation...into social practices through scaffolded and supported interaction with people who have already mastered the Discourse.... If you have no access to the social practice, you don’t get into the Discourse, you don’t have it’ (1990:147). At first glance Gee’s assertion leaves this study aground on a fairly substantial obstacle, but Gee goes on to recognise that acquisition can be facilitated in a teaching context: ‘Acquisition must (at least, partially) precede learning; apprenticeship must precede ‘teaching’ (in the normal sense of the word teaching⁴)’ (1990:147). Gee also acknowledges that learning in relation to engagement with the ways of speaking, valuing, acting and thinking of a community, facilitates the development of what he terms ‘meta-knowledge’ (1990:147). The meta-knowledge is about not only the new discourse community with which we engage, but in addition encourages a new critical awareness of the discourse community(ies) of which we are already a part. I would argue that a sociocultural perspective such as that proposed by Wells (1999), which includes a deliberate awareness of discourse, can provide a learning experience. As I will suggest, learning can be facilitated through experiential learning with a deliberate concern for affective learning (7.3.1, below). *Engagement in the discourse* of chronic illness as it relates to medicine-taking decisions is, however, not the same as being able to ‘know’ exactly what a person, even ourselves, will do in such situation.

While Chouliaraki has some questions about the compatibility of critical realist ontology

³ Note that in Gee’s usage ‘Discourse’ (capital ‘D’) refers to the social grouping or discourse community (Gee 1990).

⁴ Gee earlier defines what he understands by this usage of teaching as ‘explanation and analysis, that is, the breaking down of the thing to be learned into its analytic parts’ (1990:146). I would argue that this reflects a somewhat narrow conception of teaching, akin to Pratt’s ‘transmission perspective’ (Pratt, Aseneau & Collins 2001:2).

and discourse theory and analysis, preferring a feminist constructionist ontology combined with a realist epistemology, she does argue that a combined critical and realist approach offers greater direction than those of Habermas, Bourdieu, and Laclau and Mouffe (Chouliaraki 2002). Fairclough engages more positively with critical realism, arguing that critical realism and semiotic analysis (in particular, Critical Discourse Analysis [CDA]) are mutually beneficial and can inform each other (Fairclough, Jessop & Sayer 2002), a position supported by Bhaskar (2002). Fairclough *et al.* argue among other things, that they:

...do not reject the hermeneutic approach; rather...that hermeneutics by itself cannot provide an adequate explanation of social phenomena even at the level of face-to-face communication and interaction. There is always an extra-semiotic context to the operation of hermeneutics...and any serious explanation of social phenomena must be adequate at both the level of meaning and at the level of social (extra-semiotic) causation (2002:9).

I began this section with reference to critical realism's claim that epistemology cannot be collapsed into ontology: knowing is never identical to reality. One of the consequences of this is that we can never completely know anything. Our incomplete knowledge thus leads to corrigible reproductions and transformations in the world. This is acutely so in healthcare and medicine which is surrounded by uncertainty and risk.

3.2 Knowing, uncertainty and risk

Risks are not the same as destruction. They do not refer to damages incurred. If they were, all insurance companies would be made bankrupt. However risks do threaten destruction. The discourse of risk begins where trust in our security and belief in progress end. It ceases to apply when the potential catastrophe actually occurs. The concept of risk thus characterizes a peculiar, intermediate state between security and destruction, where the *perception* of threatening risk determines thought and action (Beck 2000: 212 – 213).

There is a sense of the loss of the absoluteness of knowledge which is reflective of the 21st century world in which we live, a world Barnett (2000a-c) calls *supercomplex*. *Supercomplexity* recognizes that – in contrast to the post-modernist enterprise – we do not live in a world in which meta-narratives have died, but rather one in which such knowledge frameworks have multiplied (2000a:416). We live now in a world conscious of:

contestability, changeability, uncertainty and unpredictability ... These four concepts are surrounded by others such as change, turbulence, risk and chaos. Together, this set of concepts mark out the conceptual geography of our supercomplex age as an age of fragility... It is an age in which nothing can be taken for granted. In short, all bets are off. It is an age of conceptual and, thereby, emotional, insecurity (Barnett 2000a: 415 – 416).

Barnett's understanding of supercomplexity is worked out against the background of the university and the curriculum (2000a; 2000b), but he links supercomplexity in the understanding of knowledge to the wider concept of a *risk society* (Giddens 1995 in Barnett 2000b:257). Not surprisingly the concept of a *risk society* has increasingly been recognized as having a bearing on healthcare-related research (Nettleton 1995; Annandale 1998; Beck-Gernsheim 2000; Traulsen & Bissell 2003).

It is important to distinguish 'risk' used in this way from the technical usage in 'risk assessment' and 'risk management'. Beck extends the idea of risk from isolated specificities to describing the nature of modern industrial society (Beck 2000). Risk is understood as 'manufactured' and always political. Its very basis lies in its potential, not its realisation:

The essence of risk is not that it *is* happening, but that it *might be* happening. Risks are manufactured, not only through the application of technologies, but also in the making of sense and by the technological sensibility of a potential harm, danger or threat. One cannot observe a risk as a thing-out-there – risks are necessarily constructed. However, they are not constructed on the basis of voluntary imagination: that is, we are not free to 'construct' risks as we please. Instead risks are being revealed in their construction (Adam & Van Loon 2000:2).

*Risk*⁵ understood in this sense refers in part to the result (the 'unintended consequences' – Beck 2000:215) of the impact of high levels of technology on and in the world in which we live. In pre-industrial society risk was related to natural events, the insurer's 'Acts of God', however:

current innovations generate risks that are more pervasive, elusive and potentially catastrophic than did previous innovations. In the "risk society", humans are becoming increasingly vulnerable, risk is seen as an inevitable and inescapable consequence of global modernisation and the multiplication of risk in society cannot be avoided (Traulsen & Bissell 2003:253).

Earlier industrial understandings of risk during the late 19th and early 20th centuries

⁵ I shall use the italicised form when referring to *risk* in the sense of a *risk society* to distinguish this usage from the more conventional (but related) usage of risk in connection with medicine usage or therapeutic options.

involved a discourse of risk related to identification and avoidance. By the 1960's this discourse shifted slightly to accepting the impact of rapid industrialization of the world and the concomitant need for a concept of 'acceptable risk'. Out of this arose the discourse (and 'science') of risk assessment and risk management (Traulsen & Bissell 2003). Without abandoning the perhaps increasingly tenuous ideas of risk assessment and management, late-modern discourse has shifted to *negotiating the meaning of risk* (Nettleton 1995; Annandale 1998; Traulsen & Bissell 2003) or perhaps more pointedly, *risk definition* (Miller 1999). Giddens argues that the *risk society* is older than Beck's attribution of modernity, and is linked to the rise of industrialization itself (Traulsen & Bissell 2003). Giddens agrees, however, with the principle that *risk* is no longer thought of primarily as the result of fate and Acts of God(s), but now as the result of human social, economic and technological processes (Nettleton 1995; Traulsen & Bissell 2003).

It is not, however, the quantitative increase in risks, nor the fact that much risk is now the result of human action that characterises the *risk society*, but primarily the fact that greater access to information (especially with regard to health-related concerns) has meant that who *defines* risk, or whose perception of *risk* results in change, is now contested. Risk definition / assessment is not (if it has ever been) a matter of science and economics alone, but is overtly political and moral (Mythen 2004). While technological innovation has not always increased the dangers which lurk behind *risk*, technology has made more information available (such as amniocentesis, satellite information gathering and the epidemiological forecasting involved in the SARS outbreaks) and the mass media interprets and communicates that information faster to more people than in the past (Miller 1999).

The conflict of knowledge frameworks referred to in Barnett's supercomplexity is then a significant element of the *risk society*. The knowledge used to 'define' risk has become increasingly a site of contestation between the 'expert' and 'lay' knowledge frameworks (Healy 2001; Traulsen & Bissell 2003). These conflicting knowledge perspectives resonate with the biomedical and lay perspectives on disease / illness, for as Traulsen and Bissell note (2003:253), expert knowledge is assumed to lie in 'scientific rationality' while lay knowledge is rooted in experience. *Risk* negotiation is thus fraught with difficulty as scientists (experts) 'determine' (calculate and pronounce on) *risk*, while the layperson 'perceives' *risk*. This leads to the expert dismissing lay perceptions as uninformed, and the layperson mistrusting, misunderstanding and rejecting (either overtly or covertly) the

advice (instructions?) of the expert (Healy 2001; Traulsen & Bissell 2003). At the same time the increasingly complex levels of *risk*, make risk calculations more and more difficult and unreliable, serving to exacerbate the loss of trust between expert and layperson (Nettleton 1995; Giddens 1990 in Traulsen & Bissell 2003). This very struggle for the power to define *risk* is the primary characteristic of the *risk society*: “‘Risk’ and the ‘(public) definition of risk’ are one and the same”, argues Beck (2000:213). Simply put, although *risk* is not ‘constructed on the basis of voluntary imagination’ (Adam & van Loon 2000:2), if the public perceive *risk* – or indeed if the ‘experts’ perceive *risk* – and act on that perception, then *risk* exists, is real (on the causal argument noted by Bhaskar above).

A further characteristic of the *risk society* is evident in the way expertise is no longer recognised as ‘objective’ (Healy 2001). Arguments for scientific objectivity increasingly fail to impress the wider population:

It is not just that the veracity of this [objective expert] approach is being questioned, but that the erosion in authority of traditional institutions correlates to a widespread public perception that the imposition of decision-making on these terms simply acts to privilege political or corporate interests. Now while many continue to maintain that current imperatives reinforce the necessity for such rational models of decision-making others are coming round to the view that these approaches are themselves pivotal to current problems. This latter view does not reject science and technical expertise as the best sources of knowledge on natural phenomena and their material application, but it does regard them as only one component in decision-making, viewed as a process that privileges human considerations rather than ‘facts’ (Healy 2001:42).

One example of this is reflected in Beck’s (in Healy 2001:41) reference to the inability of nuclear power plants to obtain private insurance, despite claims to safety – quite simply, the insurance industry (using their own experts) cannot accept the *risk*.

Another knowledge-related aspect of the impact of the *risk society* lies in the way the explosion of risk means that ‘the individual increasingly stands alone, looking for security in the face of uncertainty and an implosion of knowledge-systems. While arguably reflexivity may increase ‘...“health awareness”...being forced to make choices faced by accessing an array of expert information, under conditions of uncertainty, can create considerable anxiety’ (Annandale 1998:19). This paradoxical, unavoidable idea of *risk* closely resembles the descriptions of living with chronic illness proposed by Frank (1995). Chronically ill people live in what Frank calls the ‘demilitarized zone’ between being

cured, and yet living with illness (1995:9). As noted in the quotation from Beck with which this section began: 'The concept of risk...characterizes a peculiar, intermediate state between security and destruction, where the *perception* of threatening risks determines thought and action' (Beck 2000:213).

A consequence of this characteristic of *risk* is that 'risk reverses the relationship of past, present and future' (Beck 2000:214). Giddens' interpretation is that future-centeredness is in a new way a characteristic of late-modern society, and it is this that raises *risk* to the forefront, rather than simply an increase in risk itself (Giddens in Mythen 2004:140). We now act, determined not so much by the past, but driven by the possibility of the future: what *could* happen drives actions, rather than what *has* happened. Even this reversal contains elements of paradox, for the past intrudes into risk decisions, for knowledge 'about risks is tied to the history and symbols of one's culture...' (Beck 2000:219). An illustration of this may be found in a news item from *SAfm*, a radio news station of the South African Broadcasting Corporation (SABC). The item was published on the SABC's online news site the same day, Tuesday 7 March 2005. The item, entitled 'Create a culture of vaccination', reports on a call by medical experts urging South Africans to act now to prevent a possible health disaster:

One precaution South Africans can take in the advent of an expected influenza strain evolving from Southeast Asia's avian flu is to have routine vaccinations. Professor Barry Schoub, the executive director of the National Institute for Communicable Diseases, and Dr Andrew Jamieson of the SAA-Netcare Travel Clinic, said today that developing a culture of being vaccinated would help progress the logistical framework within which influenza vaccines would be provided to South Africa in the event of a pandemic. *So far, there is no vaccine available to fight avian influenza and there has been a high mortality rate among the handful of people in the world who have contracted it. Almost all have worked directly with poultry. However, once a vaccine is produced, it will be allocated on the basis of past use, says Jamieson...*

Schoub added that South Africa drew up [*sic*] influenza pandemic disaster management plan in 1999 - before the present avian flu alarm. "Pandemics are rarer than the influenza strains that come every winter. They come in cycles of 10 to 50 years and the last one was in 1968." Jamieson said that for the first time virologists were "watching a virus turn into something dangerous" and feared that it could turn into a virus transmissible between humans. "*We are due for a pandemic*," he said. Previous pandemics happened in 1918, 1957 and in 1968. He said that as a worst case scenario, it could be worse than the pandemic of 1918 when between 40 and 100 million people died, if the virus

was similarly serious (South African Broadcasting Corporation [SABC] 2005 *Italics added*).

Here a number of social actors and structures (academia, medicine, industry, and the media) are actively involved in defining risk, and clearly the report reflects a use of the past to add weight (fear) to the future threat to motivate a present action. The item also reflects another ideological characteristic of the *risk society*, that of driving a society to act. In this instance, to drive South African society to develop ‘a culture of being vaccinated [in order to]...help progress the logistical framework within which influenza vaccines would be provided to South Africa in the event of a pandemic.’ This statement is rooted in the commercial processes through which one country’s access to vaccines manufactured in another country, is based on their purchasing record. This record places them in a hierarchy on the buyers list, a list in which the claims of the country of manufacture are first. Thus although we are acting based on a possible future scenario, the past intrudes to add urgency to the way *risk* is constructed.

Beck argues that: ‘The more threatening the shadows that fall on the present day from a terrible future looming in the distance, the more compelling the shock that can be provoked by dramatizing the risk today’ (Beck 2000:214). Annandale (1998) illustrates this with reference to amniocentesis (a prenatal diagnostic procedure using amniotic fluid removed from the uterus to assess the probability of genetic abnormality), but examples from modern medicine are legion: decisions about Anti-Retroviral (ARV) treatment for HIV/AIDS; chemotherapy and / or radical mastectomy in the case of breast cancer; organ transplant in the case of kidney, liver or heart failure, and – more pervasively – decisions around body-image ‘products’ ranging from plastic surgery to diet / weight-loss products and programmes (Annandale 1998). *Risk* is closely tied to the ‘*logic of control*’ which underpins technological modernity (Beck 2000:215 – 216). Beck’s concern is not to deny the validity of *risk*, but to call attention to its *manufactured* nature. In so doing we are alerted to the ideological nature of risk negotiation, something which is central to interactions between healthcare practitioners and patients.

Living in a *risk society* presents an almost apocalyptic present, let alone such a future. It is this profound pessimism that has spurred the strongest criticism of Beck’s case. Mythen (2004 – following Lash 1993; 1994 and Wynne 1992; 1996) argues that Beck’s thesis is inadequate for a number of reasons. Primary among these are that Beck:

- fails to recognize both the influence of the cultural background involved in risk definitions,
- pays scant attention to human agency,
- misinterprets changes in the social positioning of expertise as the collapse of expertise,
- over-emphasises cognition and (scientific) rationality at the expense of aesthetics and experiential knowing, in information exchange regarding risk,
- exaggerates the dependence of lay people on scientific expertise in formulating lay perceptions, and
- resorts to binary understandings of relationships (such as trust) when social reality is far more complex (Mythen 2004).

While these criticisms significantly undermine Beck's thesis as a unitary model for understanding (late) modernity, they in some way emphasise significant elements: risk is constructed; technology is implicated in the construction of risk; there are multiple epistemological frameworks at work in risk construction; relationships with expertise are ambiguous; trust (in science or other expertise) is not absolute, risk is ideological and decisions for the present are taken based on perceptions of risk.

It is these insights that are important for understanding the relationship between the patient and the healthcare practitioner. This is especially so, as I shall argue later, in the context of chronic illness (4.4 below). Their importance lies in recognising the role risk construction plays in definitions of health, disease and illness, and in decisions regarding the responses to the way these are experienced by both expert and layperson. For as Giddens argues, it is in responding to the choice offered in the face of *risk* that the layperson (and indeed the expert) can exercise what Giddens terms 'reflexivity' in her / his negotiation with expert / lay knowledge (Traulsen & Bissell 2003:254). To some extent Beck (2000:215) acknowledges this when he argues that in a *risk society* 'the question we must ask ourselves is: How do we want to live?' It is in trying to answer this question, Beck argues, that expert knowledge by itself is insufficient; interdisciplinary knowledge is needed because we need 'in equal measure sure insight into technical know-how and familiarity with cultural perceptions and norms' (Beck 2000:215).

It is here in this interdisciplinary reflexivity that Bhaskar's *judgemental realism* helps prevent a slide into enervating relativism when faced with the plethora of knowledge

frameworks: claims to knowledge must be held accountable to the reality to which they refer (Bhaskar 1978; 1979; Abraham 2002). Or, to use Well's 'Spiral of knowledge' (Figure 3-2, above), knowledge claims cannot simply rest on unexamined accounts of experience, but must be examined in the knowledge-building process against information available, and tested within the community of knowledge, then once again tested against experience. Such a perspective is congruent with Giddens' understanding of the reflexive dimension of living in a *risk society* (Traulsen & Bissell 2003), and Adam and van Loon's position that risks 'are not constructed on the basis of voluntary imagination'(2000:2).

3.3 Understanding illness, understanding pharmacy

As noted above, understanding involves access to socially mediated knowledge artefacts, to the knowledge-building community, and the values, attitudes and practices of the social community in which the knowing must occur, (which suggests a reflexive knowing). For the purposes of this study then, it is important to have access to the values, attitudes and practices of both the chronically ill and pharmacy practice, in order to suggest ways in which pharmacy education may facilitate access by pharmacy students to the supercomplex, *risk* world of chronic illness. It is to an understanding of health, disease, illness, and chronic illness that I now turn.

Chapter 4 : Health, Disease and Chronic Illness

We live in an era obsessed with health and fitness, in which ‘perfect health’ is seen to have its corollary in ‘total fitness’....An illusory ‘perfect health’ is more and more being regarded as the norm, the undisputed prerogative of an unmarked version of humanity; and any hint of waywardness or defect, variance from established norms of weight or shape, deformity or disfigurement, is perceived as a type of deviance, indicating a marked and lesser humanity....[But]Health is by no means the ‘natural’ state of human beings, even if it is the preferred one (Gwyn 2002: 6-7).

4.1 Introduction – beyond commonsense understandings

Reflexivity, I have noted, is the *critical awareness of my own internal deliberation upon external reality (including situations not of my making or choosing and including both persons and the social) which can profoundly influence what I do about that reality, including social structures*. Reflexivity has both individual (‘we can modify ourselves by reflecting upon what we most care about’) and social causal powers (‘as incumbents of [social] roles, actors need their reflexivity to know that the associated duties belong to them, themselves’) (Archer 2003:41 and 2.3.4. above). Pharmacy students (as indeed pharmacists and other healthcare professionals) need to consider how they understand the natural *and* social realities of health, illness and disease as these are central to the social role — ‘the associated duties [that] belong to them’ — of the pharmacist.

4.1.1 *Reconsidering the lexicon: health, disease, illness and sickness*

Everyday usage treats ‘illness’, ‘disease’ and ‘sickness’ essentially as synonyms, while ‘health’, is defined by absence rather than as a positive experience, appears as their antonym. Roget’s Thesaurus (1996) illustrates the commonsense synonymous usage of disease, illness and sickness, as simple opposites of health. Within the sociology of health and illness, however, distinctions made in the usage of these terms offer healthcare workers, including pharmacy students, a more nuanced perspective of the field of healthcare, and in particular of the pharmacist – patient¹ space (Faber, de Castells & Bryson 2003). Although there is extensive coverage of these concepts in the literature (Parsons 1951; Herzlich 1973; 1995; Kleinman 1988; Gerhardt 1989; Lupton 1994; Nettleton 1995; Annandale 1998; Traulsen & Bissell 2003 & 2004) with the exception of Traulsen and Bissell, very little attention has been given to relating these insights to pharmacy. There is also a range of understandings of these concepts offered in the literature, but only recently have the

¹ Please see Glossary for an explanation of my use of ‘patient’.

issues raised by the idea of ‘*risk*’ been considered. As the concept of illness is central to this study, and as I will argue, ‘illness’ cannot be understood aside from its relationship with ‘disease’ and ‘sickness’, this chapter will attend in some detail to the understanding of these terms.

While recognising that we inevitably function from within one or other meaning of ‘health’, ‘disease,’ ‘illness,’ or ‘sickness’, I have chosen to use the word ‘understanding’ rather than ‘definition’ in order to signal the complexity of the concepts underlying each of these words. ‘Definition’ suggests a clear-cut understanding (‘a formal, concise statement of the meaning of a word, phrase, etc...the act of making definite’- *Collins English Dictionary*), while none of these terms appears to have definite, unambiguous meanings. In some sense defining them has the potential to silence meanings that may influence people’s actions. Awareness of the way these terms have been understood, may serve to better prepare students in considering the practice of pharmacy with respect to advising and supporting people living with chronic illness.

4.1.2 Coming to an understanding

Using a German distinction, Schwandt (1999:452) distinguishes between *knowing* and *understanding* thus:

We express the difference between knowing and understanding in German with the questions, “Woher weißt du das?” (“How do you know that?”) and “Wie verstehen Sie das?” (“What do you make of that?”).

Schwandt argues that in qualitative inquiry we are not looking for ‘an absolute account of reality’, but rather (in keeping with Bhaskar’s *judgemental rationalism* – Section 2.3.1 above) seeking the ‘truth of the best account possible. It is the truth that is disclosed by the better – the more perspicuous, the more coherent, the more insightful – of competing interpretations’ (Schwandt 1999:454). Such an approach does not deny the reality underlying the phenomena we are attempting to describe, but recognizes that social phenomena are conceptualized in vastly different ways in different geo-historical, socio-cultural contexts, and even within apparently unitary contexts (Schwandt 1999; Gwyn 2002). Healthcare professionals, for example, cannot safely assume common understandings of the concerns presented by a patient to be held among themselves, let alone between themselves and their clients. Toombs illustrates this graphically:

... as a person with central nervous system disease and a concurrent vascular disorder, at one time I was under the care of a neurologist, a urologist, a hematologist [*sic*], a gastroenterologist, a gynecologist

[sic], and a vascular surgeon (not to mention the numerous technologists associated with these professionals). Each specialist was focused on a different bodily mechanism, each was "in charge" of that portion of my body, but no one was "in charge" of the whole (in either the mechanistic or holistic sense) – except for me and, at the time, I felt the least qualified for the job! Indeed, since these specialists did not agree with one another on the best course of action, I had the feeling not only that my body was the "battlefield" on which disease processes were being fought but that a "war" was being waged on the professional front as well (Toombs 1995: 12).

The social sciences view healthcare as a sociocultural practice, recognizing that the way we engage in healthcare 'depends on the ways in which health, [illness] and disease are construed' (Cherry 2000:519). Threats to health such as the syphilis outbreak in Europe in the fifteenth and sixteenth centuries, and the global threat of HIV/AIDS five hundred years later, illustrate that the ideological nature of the construal of health, disease and illness, is neither innocent nor without cost (Cherry 2000). It is, therefore, unsurprising that arriving at a single overarching (and therefore law-like) definition of health (or disease or illness) able to satisfy every eventuality, is likely to be an impossible task (Annandale 1998; Cherry 2000; McElroy & Jezewski 2000; Corbin 2003). Health, like *risk*, is a construction taking place in the intersection of increasingly diverse frameworks.

That such fundamental concepts as health, disease and illness are so difficult to pin down signals the *supercomplexity* (Barnett 2000a) which marks the world in which pharmacists (and patients) must engage. The best that healthcare professionals and patients can do is to work together in framing responses to the question 'What do we make of health/illness/sickness?' Because understanding is *intersubjective*, it is created in shared activity (Schwandt 1999). Understanding, however, is also dependent on the world around us. As with *risk*, understanding is not unrestricted imagination but is constrained by our living in the world (Schwandt 1999).

The intersubjective nature of understanding leads to a further characteristic of understanding, one which is congruent with supercomplexity, and may help to gain a deeper insight into health, disease and illness. When attempting to understand something (or someone) we find ourselves in the unsettling place between what Kerdeman terms 'home' and 'exile' (Kerdeman 1988 in Schwandt 1999:157 – 8). We move between what is familiar (and comfortable) to us, and what is unfamiliar, new, different and perhaps

threatening to us. It is only when we are able to reflexively acknowledge the perspective from which we view the other, that we are able to understand that the new is 'Other', and we are able to risk what Schwandt calls 'a genuine conversation' in search of common meaning (1999:458). This closely resembles Harraway's (in Tong 1997:157 - 158) concept of 'epistemological conversations', for as Schwandt notes:

...common meaning can arise only in a dialogue wherein one does not simply defend one's own beliefs or criticize what the other believes, but rather seeks to become clear about oneself, about one's own knowledge and ignorance (Schwandt 1999:459).

Schwandt's phenomenology of 'understanding' helps us to consider how health, disease and illness can be construed in the supercomplex world. Such an 'understanding' also offers the potential to overcome the conceptual gridlock inherent in the paradigmatic discourse which has dogged health-related conversations between professional and laity, and medicine and pharmacy. By recognizing the intersubjective nature of understanding, the kind of experience recounted by Toombs (above) could become the exception and not the norm in the experience of chronic illness.

4.2 Health?

Everyday conceptions of health in effect construct different 'healths'. Health is 'experienced as complex entities rather than simple unities'(Herzlich 1973:53): in effect as a continuum of health which permits readings of health that include being sick and healthy at the same time. It would be easy to reject 'everyday' construals as rooted in lay ignorance. That, however, does not assist healthcare practitioners in either understanding or supporting the patients with whom they work. Health as a concept is complex, ill-defined and plural (Herzlich 1973; Nettleton 1995; Gwyn 2002), suggesting that assumptions about shared unitary or dualistic health-not-health understandings, contribute to miscommunication and misunderstanding between healthcare practitioner and patient (Payne-Jackson 1999). In her discussion of the definition of health, Nettleton (1995:41) compares four common definitions that provide some indication of the complexity of what at first appears a simple task. Health is:

- 'the absence of disease' (the *negative or absence* definition frequently used in biomedical discourse);
- 'a state of complete physical, psychological and social well-being' (a *positive or presence definition* developed by the World Health Organisation [WHO], often found in a biopsychosocial discourse);

- a *functionalist* definition which refers to ability to participate fully in society (e.g. ‘the ability to realise goals which are necessary and together sufficient for minimal happiness’ - Nordenfelt in Hofmann 2002:655). This is frequently characteristic of lay discourses of health); and
- *experiential* definitions which refer to a self-defined concepts, also often found in lay discourses of health.

Studies across a wide range of cultures reflect gender and class differences (both in combination and separately) in understandings of health. Women – especially working class women – expressed what is essentially a *functionalist* understanding (Nettleton 1995). Men, and in some studies middle-class women, adopted a *positive/presence* usage similar to that of the WHO. However, the picture is further complicated in that some Western-based studies show that age also influences health discourses, with responses ranging from experiential-functionalist through to negative usages, across age ranges (Nettleton 1995; Lawton 2003).

In a publication by the American Pharmaceutical Association (APA), Rovers, Currie, Hagel, McDonough and Sobotka (1998) appear to reflect an underlying *positive presence* conceptualization of health. They acknowledge that socio-economic factors, personal, social and cultural values and beliefs, all influence health-related decisions and actions. Harding and Taylor (2002b) reinforce this understanding of health for pharmacy practice, arguing for a socio-economic understanding of health to ‘supplement’ the biomedical model (2002b:485). Key South African government legislation also appears to assume an implicit *positive presence* understanding of health. Despite a comprehensive list of definitions regarding almost every aspect of healthcare, the South African *National Health Act* (S.A. Government, Government Gazette, No 26595, 2004) does not make explicit its usage of the term ‘health’. The nearest the Act comes to suggesting an official understanding is in the ‘definition’ of *health research*, which includes ‘biological, clinical, psychological or social processes in human beings’ (S.A. Government, Government Gazette, No 26595, 2004: 12), suggesting some alignment with the WHO definition.

It is, as Annandale (1998:262) muses, ‘notoriously difficult to access concepts of health (rather than illness)’ and any definition selected ends up ‘making someone ill’ or could deny someone as ill. In a society in which health is increasingly viewed as a matter of personal responsibility (Beck-Gernsheim 2000), and which reflects an understanding of health / disease in moral terms, concepts of health can have consequences beyond the

immediate embodied suffering of an individual. For this reason ‘what we make of health’ becomes important to pharmacy professionals and patients alike.

Any discussion of disease or sickness (and by implication, health) must begin with an understanding of the way in which humanity has understood the reality of the human experience of embodiment (Turner 1987). Turner argues that generally cultures have responded to the management of embodiment through three social institutions: religion, law and medicine (although clear distinctions between these have rarely been apparent). From around the fourth century, Christianity began to dominate as the form of religious expression in the West. Initially healthcare was subsumed under the practices of the church, with formal rites and functionaries developing to facilitate and control response to disease (Turner 2000; Parsons 1978 in Shilling 2002).

Reflecting the underlying concern for the spirit, and traditional biblical association of sin with the body, disease was regarded as primarily a matter of sin (Turner 1987; 2000; Lupton 2000). Unpredictable and mysterious, associated with death, disease developed an almost schizoid characteristic. It was a result of sin (since it was a bodily manifestation), but it was also a path to salvation through disciplined obedience and through suffering, resulting in a final release of the soul. The strong Greek influence on Christianity brought an emphasis on self-discipline and asceticism to both medicine and the body. This emphasis continues to this day, although with shifting theoretical explanation (Turner 1987; 2000; Beck-Gernsheim 2000; Shilling 2002).

The late 16th century religious Reformation in Europe which resulted in the rise of Protestantism emphasised individualism and gave further prominence to discipline, cleanliness and increasing regulation to regulate and control the body. Diet, an element of Greek medicine, gained new impetus under Protestantism as a way of controlling the body and disciplining the mind. This approach was rooted in the dualism between the body as the ‘flesh’, a symbol of desires and sin, and the soul, pure and awaiting release from the body. Disease or sickness, through its association with the body and sin, has long had about it a sense of sin and evil, but it was at the same time ‘The speediest beast carrying you to perfection...’ (Meister Eckhard in Beck-Gernsheim 2000:124). This served to position *health* in a moral discourse that is as paradoxical as disease – it was both a ‘gift of God’ and the result of faithful obedience (Turner 1987; 2000). Health was either a gift or a result of obedience, while illness and disease were thus either punishment for sin or

refining device – either way they served as preparation for the afterlife. It is this understanding that informed the 1950's – 1960's conception of health as being a functional requirement for a society, and illness became in effect a form of social deviance (Parsons 1951; Gerhardt 1989; Lupton 1994).

With the rise of science and industrialization, the individualism already evident in Western Protestantism shifted from the individual as a site of divine action, to the individual as a 'responsible citizen'. Initially this was still expressed in relation to faith, but as faith in God was replaced by faith in humanity, or more exactly – faith in technology:

What remains is the individual in the here and now and his or her physical condition. When faith in the world beyond has been dissolved, health gains in significance and value, it turns into the expectation of earthly salvation....In other words, salvation has been dethroned; healing has taken its place' (Beck-Gernsheim 2000:124).

This view is associated with what Lupton refers to as 'commodification' of the body. Here the body is represented as a commodity to be trained, sculpted, pampered and shaped until it is able to achieve 'maximum market value' (Lupton 1994:36). The body marked by disease / illness represents a failure to achieve what is expected (socially). Even aging became pathological (an 'un-health') and disability remained marginalising (Lupton 1994).

The linguistic roots of Western concepts of 'health' lie in the old German and Anglo-Saxon words for 'whole', 'hale', and 'holy', all reflecting the concepts of cleanliness and godliness (Marks, Murray, Evans & Willig 2000:3). Such linguistic roots and their associated beliefs, values and attitudes, easily lend themselves to the moral-judgemental discourses of health evident in Gwyn's comment with which this chapter begins (Gwyn 2002). These moral discourses of health in the West soon attached themselves to the idea of health as individual responsibility (Beck-Gernsheim 2000). The 'responsible citizen' discourse has significant ideological implications for healthcare in general, and for people living with chronic illness in particular:

...within advanced liberal societies, it is becoming less acceptable to enter and remain in a physically incapacitated state: it clashes too uncomfortably with the image of the 'good citizen' as someone who actively participates in social and economic life, makes rational choices and is independent, self-reliant and responsible. Chronic illness is increasingly viewed as culpability in the face of known risks, an instance of moral failure that requires the intervention of a range of political technologies (Galvin 2002: 108).

Closely allied to the 'responsible citizen' discourse is the technological discourse of control of the self (including the body) which includes 'self-knowledge, self-mastery, and self-care' (Lupton 2000:57). Mythen reflects that one way in which the discourse of responsible health is apparent in the increasingly secularized West, is in new 'ceremonial practices' that have replaced old religious practices as ways of managing 'risks to the self' (Mythen 2004:144). The rites that manage health risks still include diets, consuming herbal remedies, and discipline, but now the goal is not controlling the passions, but maintaining the body.

Examples of the range of constructions of health noted above are, illustrated in the discourse of a pharmaceutical company advertisement from March 2005 (Figure 4 -1 below). The advertisement appeared in a consumer magazine from a lifestyle chain of stores, which became the first supermarket pharmacy chain in South Africa. Moducare®, the product advertised, itself reflects the *risk* element of health discourse. While it may well be used to support recovery, the discourse of the advertisement places it primarily as a preventative measure (therefore serving to protect against possible-but-not-yet-real disaster). A cursory examination of the Moducare® advertisement (Figure 4-1) reflects the complementary discourses of 'health as gift' (in the headline) and the 'responsible citizen' in health maintenance ('Look after it, care for it'). A construction of risk ('But, stress, poor eating habits or environmental pollutants can upset the balance and lead to infections') is followed by the warrant of expertise ('Numerous medical studies prove that Moducare® capsules, taken as recommended, have a positive effect on the immune system') with appropriate referencing in small print.



Good health is a gift
Look after it, care for it

MODUCARE *for it*

A fully functional immune system plays a vital role in keeping you healthy and active. But, stress, poor eating habits or environmental pollutants can upset its balance and lead to infections, allergic-type reactions, painful joints and muscles and chronic fatigue.

Numerous medical studies prove that Moducare® capsules, taken as recommended, have a positive effect on the immune system*.

So, care for your health with Moducare® capsules. Just the boost your immune system needs.

Moducare® is the only product with a patented 100:1 ratio of plant sterols and sterolins and is available at your pharmacy. Consult your Pharmacist for more information or visit the Moducare® website: www.moducare.com.

WIN ONE OF FIVE LUXURY PICNIC HAMPERS!
Write in and tell us about your experience with Moducare®. The authors of the five winning letters will each receive a luxury picnic hamper. Write to: Moducare® Competition, PO Box 1598, Gallo Manor 2052.
*Terms and conditions apply.

The original **SUPER IMMUNE BOOSTER**



aspen PHARMACARE

*Bouic P et al. International Journal of Immunopharmacology 1996; 18(12): 693-700. Bouic P et al. International Journal of Sports Medicine 1999; 20:259-262. Donald PR et al. International Journal of Tuberculosis and Lung Disease 1997; 1(15): 518-522. Moducare® capsules. Each capsule contains 20 mg plant sterols and 0.2 mg sterolins in a ratio of 100:1. Applicant: Pharmcare Ltd. Co. Reg. No. 1889/000252/06. Aspen Pharmacare, Healthcare Park, Woodlands Drive, Woodmead. Tel: 011 239 3400. Fax: 011 239 3438. Aspen 02005

www.aspenpharma.com
Hotline 0800 122 912

Figure 4-1: Aspen Pharmacare's Moducare® advertisement from *Clubcard* magazine. Advertisement original in colour (Murison 2005:58)

Further to the re-interpreted versions of the old rituals noted above, have been added aerobics, weight training and gym membership (Mythen 2004). For example, South African managed (health) care organisation Discovery Health, packages health as a 'responsible decision' in a way which underlines the new ritual. In this guise, blessing is not only in the new salvation of longevity, but also in distinct financial and 'social' rewards for Discovery Health members who join what they term 'Vitality'. This programme involves the measured (and verified) participation by members in activities regarded as promoting 'health'. These activities range from visiting websites to gain information, through visiting pharmacies for glucose and blood pressure checks, to (specific) gym memberships, twice-annual medical check-ups, regular HIV-tests, fitness programmes and supervised weight loss programmes (Discovery Health 2005). While voluntary, the social pressure implied (because this has direct financial benefits) is strong, and the discourse is that of the 'surveillance-society-meets-responsible-health'.

The immediate implication of such a discourse, even when voluntary, is that those who do not comply are somehow deviant – responsibility brings with it blame (Beck-Gernsheim 2000; Lupton 2000; Galvin 2002). There is a logic to this to which we may be inclined to assent uncritically. Medical aid organisations work on the basis of the healthy subsidising the sick, and illness / disease does cost a society through social policies. ‘Given these conditions, it becomes a public problem if people do not make full use of preventative measures and the possibilities of a health-oriented lifestyle’ (Beck-Gernsheim 2000:129). Within these constructions of health and illness, however, those who are chronically ill often find it difficult to escape the moral judgement of society and the healthcare industry, and frequently experience a loss of status (Galvin 2002; Faber, de Castell & Bryson 2003).

At first glance, as Beck-Gernsheim (2000) notes, it seems possible to accept ‘responsibility’ discourse as admirable. However, as we stand on the brink of what appears to be the age of genetics in healthcare, responsibility discourse takes on a chilling edge. In words that have unsettling echoes of 1930s eugenics, German philosopher Hans-Martin Sass has argued that ‘reproductive risks [are] “*irresponsible in regard to the society that accepts severely handicapped people into the community*”’ (quoted in Beck-Gernsheim 2000:131 Italics added). Because it *has* happened we cannot easily argue that medical science, and indeed society at large, will never let the ominous implications inherent in this comment reach fruition in healthcare practice. Although one might argue that genetics are still on the edges of healthcare, the shadow-side of responsibility discourse in health construal is already present in the language and practice of managed healthcare. Efficiency, productivity, treatment protocols and ‘preferred providers’ become the watchwords in healthcare. Healthcare organisations drive the decisions, eroding not only patient agency, but also the agency of healthcare practitioners (Knowlton 1998). Health decisions and choices are presented to the patient, and while in theory the patient has choices, in practice sick-leave benefits, employer’s medical plan restrictions and astronomical healthcare costs mean that ‘health’ and ‘healthcare’ are being defined by institutions whose interests are not always benign. Such an approach reflects elements of social Darwinism in which only the fittest (those either not needing healthcare or those having the resources to obtain it) survive (Turner 2000).

Moral health discourse is not solely a Western techno-economic construct with roots in Western religious traditions. Marks *et al.* (2000) demonstrate the similarities and

differences between Western and Eastern, African, and sub-continental Indian discourses of health. The Chinese health discourse remains allied to its ancient Taoist religious roots. Here health is understood as lying in the delicate balance of disharmony and equilibrium, both internal to the individual and external, involving society. This view is underpinned by a strong understanding of destiny (Marks *et al.* 2000) which presents unique challenges to developing preventative health care practices and safety-related behaviour. Ayurvedic medicine also is concerned with maintaining balance, in this case between the body (*Prakfti* – a female element) and soul (*Purusa* – the male element). In an ideologically loaded understanding, *Purusa* is considered constant, while the feminine *Prakfti* is changeable. Illness is located in blockages in flows throughout the body, with death finally occurring when all flows are stopped and *Purusa* is set free (Marks *et al.* 2000). In Africa illness and misfortune are closely related, with illness (and injury) clearly associated with the spiritual realm. Unlike in the post-Cartesian, Western dualistic worldview, the spiritual and physical worlds are a whole, and the individual cannot be separated from the communal or social. Health then becomes a spiritual discourse and involves a communal response strongly associated with moral discourse (Marks *et al.* 2000; Gwyn 2002). Unlike Western biomedical discourse, however, the African, Chinese and Indian discourses do not define health as simply a quality of the individual body. Misfortune (including disease and injury) can also lead to spirito-social repercussions for those who become ill, and disease once more becomes a sign of deviance. Lupton points out that many of the so-called alternative healthcare practices that have gained acceptance in the West reflect strongly the idea of moral-personal responsibility for an affliction, with many suggesting that cancers are linked to repressed / suppressed emotions or personality types (Lupton 2000).

Figure (4-2) is an example of an advertising leaflet distributed on a university campus in Grahamstown, Eastern Cape, South Africa in January 2005. The leaflet reflects a combination of African and Western health discourses, with disease conditions (including AIDS) sometimes labelled with Western biomedical names:

YOU HAVE VISITED HUNDRED AND HUNDREDS OF DOCTORS AND NEVER GOT HELP. IT'S THE RIGHT TIME NOW TO GET THE PROPER DOCTOR!

DR. M. BADRU SSALI

AN ASTROLOGER, HERBALIST & TRADITIONAL HEALER

A member of international council of traditional Healers. Come & see the wonders of Muti & Spiritual powers. Trust her she will not disappoint you. 15 years experience

She can tell you your problems before you say anything to her. Consultation fee payable is R30.00 only. She can treat over 80 diseases and problems at reasonable rates. Some of the diseases are:

1. Sugar Diabetes
2. Asthma
3. Insanity
4. Diarrhoea
5. One with bad luck
6. Men's penis which cannot erect powerfully
7. Women who cannot produce
8. Swollen body
9. Customers Attraction
10. Bongheha (Drop)
11. Bewitched people
12. Promotion & better pay
13. Vomiting
14. Court Cases
15. Calling back a lost lover
16. Pressure
17. Tuberculosis
18. Cancer
19. Back pains / Chest pains
20. Protecting homes, cars and shops, etc...
21. *Call the lost lover*

UTERUS, OVARY & TUBES TROUBLES

THE BRAIN
The Cranial Nerves

THE LUNGS

THE INNER EYE

THE KIDNEYS

URINARY SYSTEM

THE PELVIS

PAIN OF THE ELBOW, WRIST & FINGERS

VARICOSE VEINS

PANCREAS, GALL BLADDER & BILE

HEAD AND TROUBLE SINUS

MUMPS

POLIO

Hand with Bad Luck

PARALYSIS

DEAF

GOOD HAND FOR BUSINESS BUT PEOPLE GET JEALOUS

DON'T THROW THIS AWAY, YOU MIGHT NEED US ONE OF THE GOOD DAYS!

COME AS A WITNESS 4 THE MUTI POWERS

ADDRESS:
5B Queen Str
Grahamstown
6140
Opposite Taxi Rank
Cell: 073 448 4362

VISITING HOURS:
MON - FRI 8am to 6pm
SAT 8am to 2pm
SUNDAY by appointment only

ECONO PRINT 082 430 1839

Figure 4-2: Advertising leaflet distributed in Grahamstown, South Africa in January 2005. Note the mix of African and Western biomedical health discourses found within the leaflet.

The leaflet is written in both English and isiXhosa (the indigenous African language of the Eastern Cape). The healer, whose name suggests she is an immigrant from central, eastern or western Africa, is clearly identified as 'Dr' and favourably compared with other (lesser) doctors. Many of the images come directly from Western representations of human organs. Some of the images represent concerns not normally be found in a Western medical discourse, for example: 'hand with bad luck'; 'good hand for business but people get jealous'; 'bring back lost lovers'; 'customer attraction'; 'bewitched people'; 'protecting homes and shops'; 'one with bad luck'. Dispersed among the (longer) isiXhosa list of conditions for which the healer can provide help, are some clearly Western labels: high blood pressure (N^o 20) and cancer (N^o 5). The HIV/AIDS symbol dominates on the leaflet, and a footnote either qualifies, or perhaps identifies, the promise of help with respect to HIV/AIDS as limited to 'Help on symptoms' [sic]. The pamphlet illustrates a feature of any usage of health that is inherently social, namely the way the designated healthcare professional assumes, or is granted, authority to intervene in a very wide range of human

activity ranging from personal relationships, commercial endeavour, to matters of chance and management of the future. This is a far more thoroughgoing ‘medicalization’ of society than that which social scientists are challenging as emergent in Western society in which medical practitioners:

‘... “make decisions about employability, fitness to marry and to have children, the right to have an abortion, the time a person is allowed to die, competence to enter into contracts, adopt children or rear one’s own children, or about incarceration in mental asylums. Their authoritarian judgment is sought on correct eating, sexual behaviour and the use of leisure time”....This is the medicalization of life (Skrabaneck 1994 in Cherry 2000: 533 n.4).

The spiritual / moral discourse of ‘health = good, illness = evil’ that is evident in Figure 4-2 (above) persists in Western health discourse despite the scientific claims to authority in Western medicine (Parsons 1978 & 1991 in Shilling 2002; Galvin 2002). Figure 4-3 provides an example of pharmaceutical advertising material which illustrates one way in which moral discourse is maintained in the West.

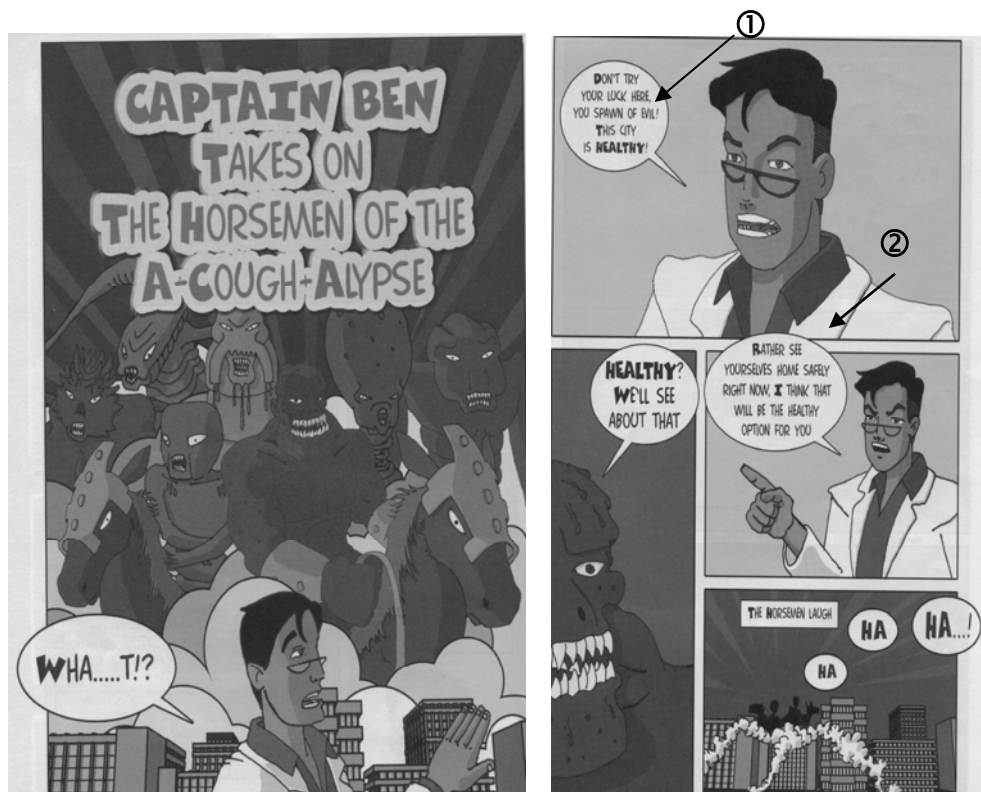


Figure 4-3: discourse of disease as evil in Benylin ® advertisement. Note the original is in colour.

The two pages illustrated in Figure 4-3 are extracts from a comic-style marketing package directed at retail pharmacy (not, it must be noted, directly at the public). The pages reflect a health discourse of moral judgement, with the ‘causes’ of cold and influenza symptoms depicted using Western cultural-religious representations of evil (‘The Four Horsemen of

the Apocalypse' now reads 'The Four Horsemen of the A-cough-alyipse' in the first page. The second page has Captain Ben – represented as the courageous (male) pharmacist – confronting the 'spawn of evil' [see inserted arrow①]). Later pages represent Captain Ben in superhero guise having swallowed 'the secret Benylin potion'. This imagery is completely at odds with Western medical discourse, suggesting that medicine (in the form of the advertised product), has more to do with the realm of magic than science, and that it is capable of transforming a supposedly healthy pharmacist into a caped superhero, who in the end is responsible for 'Defeating all the symptoms' and returning everything to 'normal'. Here 'normal', taken in the context of the accompanying images, represents an implicit 'healthy, fit and functional' model of health. The word 'healthy' is also used in a manner allied to a moral discourse, crudely translated into 'behave yourself or you will suffer the consequences' (see inserted arrow②)². The two healthcare advertisements in Figures 4-2 and 4-3 contain unexpected similarities and expected differences, illustrating the *supercomplexity* involved in the construal of health in an increasingly globalized society. Referring to what is a further facet of the supercomplexity nature of late modernity, Webster (2002) argues that any understanding of health must now recognise genetics and other rapidly advancing new technologies, and so must accommodate the concept of *risk* – a construal of health must then be able to accommodate the 'presymptomatic' (Webster 2002:447), asymptomatic and symptomatic.

The overview of constructions of health presented above reflects a surprising degree of similarity, even accepting the apparent epistemological differences. Few of the constructions of health are limited to binary 'definitions' related to absence or presence, an ability or an in(dis)ability. 'Positive presence' and 'ability' understandings dominate and with them the moral discourse of responsibility appears (Galvin 2002). This last element gives an appearance of agency, although it is a truncated agency in a society in which health bears close associations with salvation, albeit salvation in secularized form. The understanding of health is nonetheless fluid, context related and developed in ideological contestation between layperson and expert, state and commercial interests, cultural and scientific knowledge.

To define concepts of health, illness, and disease, i.e., which complaints and general circumstances ought medically to be construed so as to be understood as licitly [*sic*] within medical authority, one must

² (See the enclosed CD, /Readings/CaptBen.pps for a PowerPoint® copy of the comic component of the advertising magazine)

appeal to more than the nature of reality. Appeal must also be made to particular values and interests to ground standards of normal behavior and functional body states. Yet it is the very availability of standards which is at issue.... Therefore, one will likely need to choose between personal liberty, holding individuals responsible for their choices, and a coercive health care policy which promotes one particular conception of the good over others (Cherry 2000:531 – 2).

As much as sociology (and indeed professional healthcare) is critical of many of the construals of health, these construals nonetheless operate powerfully within society. The best that sociology can demand of healthcare professionals, is that they are reflexively conscious of the way in which they construe health, and of the way those with whom they interact may (legitimately) embody different constructions of health upon which they as patient-agents will base their health related actions.

In the light of the construals of health reflected above, I offer the following understanding of health informed by the usages proposed by the WHO and Corbin (2003):

The physical, psychological and spiritual well-being which enables a person to experience her/his actions, interactions, and appearance in a manner to which she/he has become accustomed and which permits her/him to participate in a personally meaningful manner within her/his geo-historical social structures.

In offering this construal of health I am aware that this is no more a law-like definition than any other. Within the context of seeking to grant pharmacy students epistemological access to chronic illness, this understanding seeks to recognize:

- a holistic, non-dual conception of human existence (mind and body cannot be separated any more than agency and structure);
- that ‘health’ cannot be understood in isolation from social context;
- that health cannot be understood separated from individual experience;
- that health experiences are tied up with personal meaning (Öhman, Söderberg & Lundman 2003);
- that health is imbued with moral meaning;
- that there is a spiritual dimension to health construal which is not necessarily aligned with religious institutions (McElroy & Jezewski 2000; Oman & Thorensen 2003);
- that health cannot be characterized merely by absence, but more by a positive presence;

- that health is a moment on a continuum rather than a distinct category (Nordenfelt 2000).

4.3 Disease / Illness / Sickness

The literature within the sociology of health and illness and related fields is marked by substantial references to the disease / illness debate (Cherry 2000; Nordenfelt 2000; Hofmann 2002; Nettleton 1995; Annandale 1998). The overall trajectory of the debate challenges the unquestioned adoption of the biomedical classification of ‘disease’ into a psychosocial model, as both misleading and reductive. This wide-ranging debate is surveyed by Turner (1987), Nettleton (1995), and Annandale (1998). I shall therefore offer only a brief summary using Turner’s (1987: 2) ‘neat and economic classification of human disorders’ namely disease, illness and sickness’ (see below, Table 4.i).

Term	Usage
disease	biomedical, describing biological or physiological malfunctions; reflecting abnormality
illness	subjective, reflecting the individual’s experience of [a] disorder
sickness	social designation of roles depending on society’s perception of a disorder

Table 4-i Summary of Turner’s perspectives (Turner 1987)

These classifications are normally further aligned with medical (disease), lay (illness) and sociological (sickness) perspectives respectively (Turner 1987; Hofmann 2002).

4.3.1 Perspectives not paradigms – Hofmann’s ‘Triad’

Much of the debate in the literature of the sociology of health, illness and medicine, and within medicine itself, has focused on which perspective of disease and / or illness has (or should have) epistemic and normative value in healthcare decision-making, and on what role these classifications play in sickness and vice versa. Using a tabular representation of the classifications (Table 4-i), while granting ease of understanding, reinforces the kind of paradigmatic incommensurability which appears to characterise the debate between healthcare professional, lay and social perspectives. These tensions are well illustrated in the differences of perspective between Popay, Williams, Thomas and Gatrell (1998) who argue for lay knowledge in theorising healthcare, and Prior’s (2003) at times strident case against the idea of ‘lay expertise’ as he attempts ‘to draw a boundary around the domain of expertise’ in healthcare (Prior 2003:Abstract).

As I have argued previously, paradigmatic approaches set up oppositional ‘positions’ to be occupied and defended, rather than facilitate a holistic perspective more in keeping with a supercomplex society. This is well illustrated with respect to healthcare in Toombs’ (1995)

experience of disease-focussed biomedical care in the supercomplex context of modern chronic illness. Hofmann proposes an alternative use of the three classifications in a *triadic* relationship of disease, illness and sickness *perspectives* rather than distinct paradigms.

The classification into an integrated ‘triad’ of perspectives was first formulated in 1967 by Andrew Twaddle (Hofmann 2002) (Figure 4-4):

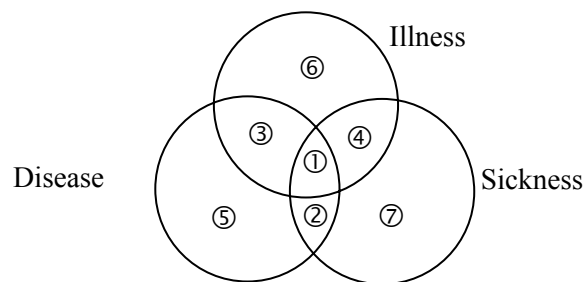


Figure 4-4: Visual representation of Hofmann's perspectives based on the original concepts by Twaddle (Twaddle 1968 in Hofmann 2002:653)

Hofmann argues that the triadic relational understanding retains adequate explanatory power in even difficult cases, can be applied independent of ‘a general concept of health’, and perhaps most significantly, ‘reveals epistemic and normative differences between the concepts, in particular a primacy of illness’ (Hofmann 2002: 667 – 668). This triadic representation uses all three constructs simultaneously, with the emphasis shifting depending on context. The central area of overlap (Figure 4-4 - ①) serves to represent the ‘paradigm case’ (2002:658). In Hofmann’s paradigm case, a person experiences *illness*, consults a medical professional who diagnoses a *disease*. The person is then recognized by her employer as being *sick*, and therefore entitled to relief from responsibilities. Other cases are accommodated, such as those in which someone is recognized by society as *sick*, and diagnosed so by medicine (*disease*), while the person does not recognize or acknowledge *illness* (Figure 4-4 - ②). This may include conditions involving action such as predictive screening which reveals genetic potential for disorder, but which has not yet occurred, and the extreme case of an unconscious person (Hofmann 2002). This may then also apply to mental illness, although this may be a special case. Position ③ (Figure 4-4) could include conditions which a person experiences as *illness* and which healthcare professionals recognize as *disease*, while society may not recognize *sickness*. Here Hofmann suggests the common cold and tooth decay (2002: 658), although I would argue that society does grant some dispensation in both cases, for example through medical aid schemes, and even sympathetic acknowledgement. Position ④ is less clear, but here he includes chronic fatigue syndrome and pregnancy (2002:658). Position ⑤ (Figure 4-4)

could include a range of asymptomatic conditions such as mild cases of hyperglycaemia (raised glucose levels in the blood), hypertension (raised blood pressure), but also conditions that remain asymptomatic until exposed to a trigger, such as lactose intolerance (Hofmann 2002: 658). These remain ‘hidden’ from both the person and society and so cannot be ‘granted’ sickness status in the case of the individual, although they may be recognised as *sicknesses* upon diagnosis. They may not, however, be recognised as *illnesses*. Position ⑥ (Figure 4-4) could include very real and unpleasant experiences such as anxiety, while Position ⑦ is intuitively very context dependent. Hofmann suggests examples from both the past and present in which society has demanded that homosexuality and delinquency be recognised as *sickness* (2002:659). Clearly, as Hofmann acknowledges, these are not exhaustive examples, but they do demonstrate that using the triadic model offers a useful interpretive framework that can accommodate both the conventional and the controversial.

The triad highlights epistemic and normative concerns for everyday healthcare (Hofmann 2002). It is immediately apparent that persons represented as being within any of ⑤, ⑥ or ⑦ (Figure 4-4) face substantial challenges convincing others or being themselves convinced, of need for action, and / or of understanding concerns expressed by others, or of having their concerns understood. It appears that it is the instances in which *illness* is absent, that some of the most difficult epistemic and normative challenges are presented. For example in the case of either ⑤ or ② (Figure 4-4), problems relating to therapeutic agreement between patient and healthcare practitioner loom very large. In these instances there could also be greater readiness to *insist on* medical intervention than there would be to *grant the need for* medical intervention (or social recognition) in the case of ⑥ only (Hofmann 2002). The triadic perspective, Hofmann argues, makes explicit the challenges to take greater cognisance of the experiences of the individual patient in diagnostic and therapeutic decision-making, as *illness* both places limits on the territory of healthcare practice and confronts healthcare with its area of least knowledge and understanding. At the same time I would argue that the model also constrains *illness* and *sickness*: society cannot simply ‘construct’ something (or someone) as requiring medical intervention without some indication of *disease* or *illness* – for example the infamous ‘drapetomania’ (from Greek *drapeto* (to flee) + *mania* (obsession or madness)) used to describe the ‘cause’ of slaves running away (Hofmann 2002:660).

4.3.2 Disease

The *Dictionary of Nursing* (2003) offers the following definition of disease:

disease (di-zeez) *n.* a disorder with a specific cause and recognizable signs and symptoms; any bodily abnormality or failure to function properly, except that resulting directly from physical injury (the latter, however, may open the way for disease).

However disease, as Scadding notes, does not *cause* a disorder:

The essentialist's hankering after a unified concept of disease as a class of agents causing illness is mistaken and misleading for several good reasons: many diseases remain of unknown cause; known causes are of diverse types; causation may be complex, with interplay of several factors, intrinsic and extrinsic; and, more generally, an effect – the disease – should not be confused with its own cause (1996:595).

The patient presents an account of symptoms from which the healthcare practitioner selects, and then proceeds to compare these symptoms to a 'symptom cluster', then identifies by supplementing the symptoms using evidence obtained from instruments (which must then be *interpreted*, be it auscultation using a stethoscope, or reading the markings off an Electro-Cardio Graph) (Mishler, referring to Balint [1957]1981:8). Disease is thus the product of a process of diagnosis, and diagnosis is an interpretive act (Good 1994 in Payne-Jackson 1999). Disease therefore is not identical with objective fact (Scadding 1996; S. Williams 2000a). Gillett illustrates this well with reference to gastric ulcers:

When I graduated from medical school, a multiple choice answer citing that gastric ulceration was a disease involving bacterial infection would be marked "wrong" with all the assurance of a positivist representation of reality. Now an answer of that type would be marked "right" because we have discovered that an infective process is critical in the development of gastric ulceration (Gillett 2004:734).

Gastric ulceration, while it appears to have an exogenous causal component, also has components of lifestyle, injury, and iatrogenic causation (for example as a result of anti-inflammatory medication usage). This common multi-causal condition further reminds us that disease, like health, remains conceptually difficult. Disease is a representation, a description of, something beyond. More specifically 'disease' is a social representation that gives meaning to specific classifications of events (Mishler 1981). Societies which see embodied disorder more holistically, even if they do grant a biophysical element, will construe that disorder differently to societies which accept a biomedical perspective. This in no way denies the presence of a reality, but interprets that reality differently and therefore acts differently. Disease therefore exists at the level of the transitive (at best the Actual), and not unproblematically at the level of the intransitive Real, although it must be held accountable to and by the Real (Bhaskar 1978; 1979; Sayer 2000).

Even though the *Dictionary of Nursing* recognises that disease is a diagnostic construction, and does not suggest a positivist identification of the diagnostic description with the underlying reality, it nonetheless presents a number of problems. Firstly, the *Dictionary of Nursing* definition reflects a self-contradictory understanding that is simultaneously reductive ('a specific cause) and inclusive ('any bodily abnormality or failure to function properly'). While disorders experienced by patients as a result of physical injury are specifically excluded from the definition, the inclusion of 'failure to function properly' extends the boundaries of medical expertise very broadly indeed. (Who defines 'failure' and 'proper function'? For example are obesity, tobacco addiction, alcoholism, shyness, a stammer, delinquency, erectile dysfunction, forgetfulness and stress, all diseases? Is a Myocardial Infarct – a heart attack – a disease or a physical injury?) In addition, there are an increasing number of disorders which appear to have complex causality or no known aetiology (Scadding 1996; Richman & Jason 2001; Gillett 2004). Examples of these range from HIV / AIDS, through Chronic Fatigue Syndrome (CFS), Irritable Bowel Syndrome (IBS) and Rheumatoid arthritis (RA), the disorder experienced by patients involved in this study. (Despite an acknowledged lack of 'specific cause', RA is termed an 'autoimmune disease' – Lee & Weinblatt 2001; Guerenlian 2002; MERK Manual 2004).

Despite the conceptual difficulties inherent in the biomedical construal of disease, the social sciences to a large extent accept biomedicine's self-definition of medical practice (Turner 1987; Nettleton 1995; Annandale 1998). However, the value of this concept of 'disease' is highly contested in social science literature (Thagard 2003). Hofmann offers what he terms 'coarse conceptions' of disease, illness and sickness which reflect the general areas of debate within the social (and to some extent, medical) sciences (Hofmann 2002: 657):

Disease is negative bodily occurrences as conceived of by the medical profession. *Illness* is negative bodily occurrences as conceived of by the person himself [sic]. Correspondingly *sickness* is negative bodily occurrences as conceived of by the society and / or its institutions. Occurrence here means process, state of event.

Nordenfelt (2000) suggests a slight but significant change of emphasis, in an attempt to soften the dualism inherent in the traditional usage, Nordenfelt argues that 'a disease (malady) is a state of a part of the human body or mind' (2000:643). These definitions assume a Western biomedical perspective and so might be better phrased 'Disease is a negative

psychobiological occurrence as conceived of *within biomedicine*'. This flagging of biomedicine is important even in the West, for as Marks, Murray, Evans and Willig (2000) and Gillett (2004) note, healthcare professionals in the West are beginning to take note of alternatives to biomedicine, which include more holistic elements from their indigenous or Eastern roots. Even the rephrased definition, however, would not do justice to the concepts rooted in sub-continental Indian (Ayurvedic medicine), Chinese or African understandings of medicine, for whom a general principle of spiritual and social connectedness would be at odds with the Western location of disease in the individual (Marks *et al.* 2000). A sociological usage would need to accommodate a range of 'medical' (as distinct from biomedical) perspectives, and here Kleinman's now classic understanding remains useful:

Disease... is what the practitioner creates in the recasting of illness in terms of theories of disorder. Disease is what practitioners have been trained to see through the theoretical lenses of their particular form of practice. That is to say, the practitioner reconfigures the patient's and family's illness problems as narrow technical issues, disease problems....The healer...interprets the health problem within a particular nomenclature and taxonomy, a disease nosology, that creates a diagnostic entity, an "it" - the disease. *Disease is the problem from the practitioner's perspective* (1988:5 *Italics added*).

Within the model of Twaddle / Hofmann's triad, I shall then follow Kleinman's understanding of disease. This still leaves the question that if disease is the 'problem from the practitioner's perspective' (however that is construed), then how do we understand the patient's perspective?

4.3.3 Illness

In the stage production of *W;t* [sic], Margaret Edson's (1999) carefully crafted play narrating a middle-aged professor of literature's dying as a result of treatment for recently diagnosed ovarian cancer, the play opens with Professor Vivian Bearing (the patient – marked as such by hospital gowns, ID bracelet, intravenous drip, and baseball cap perched on her bald head), standing centre-stage. She greets the audience in a tone of false familiarity:

'Hi. How are you feeling today? Great. That's just great.' (*then in her own professorial voice*) That is not my standard greeting, I assure you...But it is the standard greeting here.

There is some debate as to the correct response to this salutation. Should one reply "I feel good," using "feel" as a copulative to link the subject, "I," to its subjective complement, "good"; or "I feel well,"

modifying with an adverb the subject's state of being?

I don't know. I am a professor of seventeenth-century poetry,
specializing in the Holy Sonnets of John Donne.
So I just say "Fine."

Of course it is not very often that I do feel fine. I have been asked
"How are you feeling today?" while I was throwing up into a plastic
washbasin. I have been asked as I was emerging from a four-hour
operation with a tube from every orifice, "How are you feeling
today?"

I am waiting for the moment when someone asks me this question
when I am dead.

I am a little sorry I'll miss that (1999:5).

Disease-focussed discourse modifies 'the subject's state of being' through objectification of the subject, the categorization of the person into a disease, or, as in the account by Vivian Bearing, the silencing of individual experience in a glaze of 'How are you feeling today?', without stopping to hear the answer. Illness discourse, like disease discourse, is ideological – but *Illness* claims back the right to subjectivity in the face of the objectifying claims of *disease*.

Gwyn (2002) points out that the association of illness with the concept of 'lay' (see above, Turner's classifications) remains problematic because 'lay' implies a deficit understanding to be measured against 'real' knowledge, expert knowledge. 'Lay' representations of disorder are rooted in cultural understanding and include re-interpreted elements of medical representations of disease (Gwyn 2002; Fox, Ward & O'Rourke 2005). These form what becomes culturally embedded *commonsense*: representations of disease / disorder that have 'become incorporated into our consensual reality' (Gwyn 2002:35). 'Commonsense,' however, is not restricted to lay representation and can be called upon by 'experts' (be they clinicians or electricians) as much as laity (be they electricians or clinicians, respectively) to defend positions. Expert knowledge and the social recognition of an expertise which provides for accompanying social rewards, are hard won, and so competing knowledges are resisted through ridicule and/or appeals to superior epistemological authority (Gwyn 2002). Prior's rejection of 'lay knowledge' through which 'lay people had metamorphosed into multi-skilled and knowledgeable individuals; epidemiologists even' (Prior 2003:44) provides a classical example of such strategies:

Lay people do, of course, have information and knowledge to impart... they have knowledge about their own bodies and its pains (Arksey 1994, Busby, Williams and Rogers 1997), and the ways in which the body reacts to medication (Monaghan 1999, Hibbert, Bissell and Ward 2002). They often have detailed knowledge of other people as well as of themselves... and intimate knowledge about the circumstances in which they live (Popay *et al.* 1998). And all in all, they are experts by virtue of 'having experience'. Yet, experience on its own is rarely sufficient to understand the technical complexities of disease causation, its consequences or its management. This is partly because experiential knowledge is invariably limited, and idiosyncratic. It generates knowledge about the one instance, the one case, the single 'candidate' (Davison, Davey-Smith and Frankel 1991). Perhaps, most important of all, and to echo the warning of Collins and Evans (2002), we should be aware that 'the romantic and reckless extension of expertise has many well-known dangers' (2002: 271). Above all, lay people can be wrong (Prior 2003:55).

While grudgingly granting acknowledgement of a devalued form of subjective knowledge, Prior resists the challenge to the privileging of medical expertise that is inherent in calls for inclusion of lay knowledge in healthcare decisions. Prior uses the repeated assertion of the fallibility of lay knowledge to distinguish medical (expert) from lay knowledge (2003:45, 49, 52, 55). If a capacity for fallibility excludes knowledge as having value, then medical knowledge fares no better, even in its own terms: 'There is nothing new in medicine about error causing serious injurious consequences, but the increasingly hazardous and intricate character of the instrumentalities that present-day medicine deploys enhances the potential seriousness of the errors that take place' (Fox 2000:416).

Despite a tone alternating between ridicule and paternalism, Prior's caveat is important *if* what is meant by 'illness' discourse is the establishment of 'the lay expert' (Prior 2003). I agree with Prior's rejection of the 'lay expert' not only as intuitively oxymoronic, but because it suggests competing paradigms of expertise³ in the medical decision-making process. As Toombs' (1995) experience illustrates, there is sufficient expert competition within diagnostic and therapeutic decision-making already. The idea of competing knowledge-equivalent experts appears to derive from paradigmatic thinking. The very point of bringing *illness* into the healthcare triad, is that the knowledge that the patient (and/or her caregivers) brings is *different*, but not incommensurable, with that of the healthcare professional (Gwyn 2002).

³ For a consideration of the construction of 'expertise' see 6.2.2 (below).

Arthur Frank proposes that the ‘postmodern’⁴ experience of illness begins when ill people realise that there is more in their experiences than the medical story can tell’ (1995:6). Illness, suggests Frank, becomes the way patients, their care-givers, family and friends, tell their stories of disorder and loss of biographical certainty. Illness represents the patient’s story in the face of the medical story of disease. This ‘story’ is not to be confused with fictional tale, although people can of course present fictional tales of personal disorder, just as easily as healthcare professionals can through their use of technical discourse to shroud uncertainty. Illness accounts are reflexively built around a person’s experience, including their current experience of disorder, their past experiences of medical / disease discourse, information gleaned from medical discourse and the illness accounts of friends and family. To this must increasingly be added the range of internet and print media resources, including advertising of pharmaceutical and ‘healthcare’ products (Gwyn 2002). Illness understanding informs the patient’s decision to seek assistance, and presents the healthcare professional with their first access to the disorder in the form of symptoms. Based on their ‘lay’ understanding, the patient will select symptoms to present the disorder to the healthcare professional. Even the patient’s responses to questions will be informed by their illness understanding. How the healthcare professional interprets both the illness (re)presentation and the responses (proceeds with the diagnosis), will depend in part on their ability to see illness representations, not as fallible lesser accounts lacking scientific verifiability, but as perspectives on embodied disorder particular to the person seeking therapy. Viewed as a perspective rather than a competing paradigm, illness accounts contribute to the diagnostic and therapeutic capital available to both professional and patient. As such much of the significance of illness accounts lie specifically in the places where they challenge medical knowledge. This is especially germane with respect to understandings of causality and trajectory, as it will be the patient’s logic that will determine their treatment decisions – what they make of the healthcare professional’s recommendations (whether those recommendations become ‘doctors orders’ or merely ‘suggestions’).

Kleinman’s conceptualization of illness expands Hofmann’s ‘coarse definition’ (above) while remaining congruent with the triadic perspectives model:

⁴ Frank is at pains to distance his reluctant use of the term ‘postmodern’ from the ‘number of intellectual agenda[sic]’ associated with it, using it rather to refer to the late twentieth century (1999:4).

Illness refers to how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability (1988: 3).

As with Kleinman's conceptualization of disease, such an understanding of illness involves meaning-making around symptoms and signs – measured and perceived of differently using a different nomenclature and taxonomy to that of biomedicine, but not denying the reality of the biophysical. Frank (1995) and Simon Williams (2000a & b), urge that social scientists must not omit the recognition that illness involves the patient's embodied experience as well. '[T]he illness experience is an experience in and of a diseased body' (Frank 1995: 187 n.2) – something at best implicit in Kleinman's understanding (above). In order to make the somatic experience of illness clearer, an amended version of Kleinman's understanding of illness could read:

Illness refers to how the sick person and the members of the family or wider social network perceive, live with, and respond to the *embodied experience* of symptoms and disability.

So understood, illness also reminds us that the individual experience of disorder, be it from the vantage point of disease or illness, has social dimensions (McElroy & Jezewski 2000). Kleinman and Seeman argue that a fundamental dimension of illness is that '*The experience of illness is not bounded by the bodies or consciousness of those who are ill*' (2000:231 Italics in original). While biomedicine regards disease/illness in terms of an abnormality of 'the structure and/or function organs and organ systems' (Young 1982 in Kleinman & Seeman 2000:231), and illness accounts reflect specific embodied experience, illness is experienced within a network of relationships that are impacted upon by the illness experience – what Kleinman and Seeman term the "socosomatic" quality of illness experience' (2000:231). Just as disease perspectives inform illness accounts, so too do the experiences of the 'wider social network' in which these accounts are construed. It is thus necessary to consider 'sickness', the third element of the triad.

4.3.4 Sickness

Illness is always situated within a social context. However, in ways beyond a 'merely' epidemiological conception, society also contributes to the *experience* of illness (Herzlich 1973). The social context includes the specific personal embodiment of illness, the socio-cultural environment in which that experience is situated, and the way that experience is construed by society. Aside from the medical institution, wider social structures involved include: family (where 'illness' is first understood); religion (morals,

healing and explanatory power); economic institutions (employment; medical technology and/or pharmaceutical industry; commerce in the form of medical aids or managed care organisations); the media (how illness and/or medical institutions are portrayed and communicated); and the state (health policy and legislation; healthcare systems) (Herzlich 1995; Pierret 2003). Since Parson's work on the *sick role* in the 1950's, the role of society in the construal of the illness experience has been a central concern of sociology of health and illness (Lupton 1994; Herzlich 1995; Shilling 2002).

Parson's original understanding of the sick role was rooted in his functionalist theoretical perspective in which social relations are directed towards maintaining social order. Added to this was his recognition of the influence of religion, especially Protestant Christian religion, on American social understandings of illness. Central to this influence was the idea that work was the morally appropriate response to the gift of life. Failure to work was considered deviant because it constituted a loss to society through a failure to acknowledge the gift of life, and the costs borne by society to facilitate a person's birth. Illness means that a person can no longer work (even for a brief period) and this then means a loss to society. Illness thus *can* be a form of deviance, depending on whether or not the ill person adopts appropriate or inappropriate behavioural responses (Parsons 1991 [1951] in Shilling 2002; Gerhardt 1989). Parsons recognises that illness ('a state of disturbance in the "normal" functioning of the total human individual, including both the state of the organism as a biological system and of his personal and social adjustments') is both biological and social (Parsons 1951: 431). Parsons thus explicitly extends the biomedical understanding of disease to include a social dimension (Lupton 1994; Herzlich 1995; Shilling 2002), including a recognition of the inadequacy of the biomedical perspective on its own as a satisfactory explanatory model (Parsons 1951).

Based on his functionalist perspective on society, individuals worked within socially organised roles aimed at ensuring the functioning of society. As long as people operated within these roles, they contributed to the maintenance of order within society. The idea of a 'sick role' as proposed by Parsons, was linked to the idea of capacity to function. The straight-forward linking of the concept of deviance to Parsons' idea of the 'sick role' is simplistic. Illness is not viewed as deviance; it is the 'motivatedness' behind the illness which can be considered deviant (Parsons 1975 in Gerhardt 1989:15). Where a patient has what Parsons terms a '..."negatively achieved" role' (where illness is a result of a failure to

stay well), deviance is not necessarily an aspect (1951:438). Where the patient assumes a role which is positively achieved (a desire to be / stay ill) this is deviant, because a person does not accept the social responsibility of doing what they can to regain health and therefore to contribute to society (Gerhardt 1989).

Medical professionals' socially determined roles are framed around the restoration of an ill person's functional capacity to contribute to society. People who are ill have a complementary socially determined role (Parsons 1951; Gerhardt 1989; Lupton 1994). Society, in this view, grants the ill person a role (the 'sick role') which provides dispensation from normal economic activity. This role however is a behavioural role: the sick person is expected to engage in certain behaviour. This behaviour begins with accepting the 'moral responsibility to regard being sick as undesirable, as something that should be overcome as soon as possible' (Parsons 1991[1951] in Shilling 2002:624). This acceptance is followed by the 'obligation...to seek *technically competent* help, namely...that of a physician and to *cooperate* with him [sic] in the process of trying to get well' (Parsons 1951:437. Italics in original). The sick role has been presented as representing a *passive patient*, who because of technical incompetence and ignorance, is dependant upon the socially authorized medical professional.

While the criticisms of the 'sick role' have been extensive, they have focussed primarily on the lack of criticality with regard to medical knowledge and power, and the inability of the 'sick role' to accommodate illness for which the patient may be socially deemed to be responsible (Gerhardt 1989; Lupton 1995; Shilling 2002)⁵. As Gerhardt and Shilling note, this latter criticism does not adequately acknowledge the subtle distinction which Parsons made between negatively achieved and positively motivated sick roles (Gerhardt 1989; Shilling 2002).⁶ Herzlich suggests that the 'sick role' also fails to accommodate people who refuse to accept the dependence on the medical profession – either in not seeking assistance, or in acting to retain autonomy and using medical advice as just that, and not instruction (Herzlicht 1973). In a more telling criticism, Herzlich argues that the 'sick role' is focussed on, and led to a sociological focus on behaviour, and 'behaviour is

⁵ Shilling argues that sociology has done Parsons a disservice in treating the 'sick role' as a universal set of rights and obligations independent of its originating social context. Shilling argues that Parsons originally intended the concept as an analytical tool for understanding society's granting the ill person rights and dispensations, but also expectations. The misunderstandings of Parsons' intention have contributed to the severe criticism, especially by post-modern sociologists, of Parsons' insights (2002).

⁶ For a detailed account of these two roles – the capacity model and the deviance model – see Gerhardt 1989:5 – 72).

not clearly related to the way in which the individual sees and interprets the situation' (Herzlich 1973:9).

Whatever the criticisms and weaknesses of Parson's models, his work served to raise awareness that illness could not be reduced to disease: illness construals, as with health, have a social component. Numerous competing models of society's influence on illness have arisen since Parsons, among which the most prominent are: the interactionist; phenomenological; conflict – or critical – theorists (Gerhardt 1989); the social-constructivist (Lupton 2000); Marxist, cognitivist (Armstrong 2000); and the Feminist and Disability theorists (Lupton 1994). Avoiding a paradigmatic approach to these perspectives enables a fuller understanding of illness / disease phenomena (Lupton 1994). The key issue is that society does act to influence illness construals. In whatever specific socio-cultural expression, society acknowledges some illnesses and grants dispensation to people experiencing those illnesses in the form of healthcare policy, access to healthcare facilities, provision of special benefits (grants, medical aid benefits; sick leave), but also less formalized dispensation such as sympathy and acceptance of behaviours. The way society selects the illness experiences for which dispensation is granted, is of course cultural and ideological, and is frequently informed by the medical institutions in each society. In societies under the influence of biomedicine, disorders as disparate as pneumonia, cancer, physical injury, cardiac conditions (for example) are recognised as serious and those experiencing these may be granted significant social dispensation for absence from work, financial support and medical care. Other disorders receive less, if any, dispensation (acne, the common cold, menopause, erectile dysfunction), and some highly contested disorders become battlegrounds between patients, support groups, medical professionals, economic institutions, the state and even religious groups (HIV/AIDS; Chronic Fatigue Syndrome; alcoholism; depression; leprosy). What is significant in the consideration of sickness (society's construal of embodied disorder), is the power of the medical profession to grant entry into the world of the sick (Mishler 1981). 'In modern western societies the institution of medicine has an important role to play in social control, in shaping the regulation of human action, the department of human bodies and the construction of subjectivity...' (Lupton 1994:19). Disease, illness experience and sickness thus become not synonyms for biophysical malady, but perspectives on lived human experience.

The conceptualization of disease, illness and sickness as perspectives within a triad reflects the agency-structure relationship called for in both the ontological and epistemological perspectives for which I have argued. This approach also recognises the socially constructed nature of disease and illness, while not denying the discourses which underpin them, nor permitting a silencing of the body. If viewed in this way the triad also offers a significant interpretive perspective for healthcare professionals considering the negotiation of therapeutic options with people living with chronic illness.

4.4 Chronic Illness

For the chronically ill, disease is an intrinsic element of one's way of being, a permanent feature of living. Since the complete restoration of physical well-being is not a possibility, the chronically ill must learn to live with ongoing disorder – the goal being to live well in the presence of (rather than the absence of) illness. The emphasis, therefore, is not so much on confronting and vanquishing disease as it is on integrating illness and transformed bodily being into one's daily life in a positive fashion. The nature of such a challenge requires a professional and personal response that is different from that required by the temporary disruption of acute illness (S. Kay Toombs: 1995:10).

Chronic illness extends beyond the individual sufferers and their families and presents not only the healthcare professions, but society as a whole with a growing challenge. In 1999 in excess of 80% of recorded medical consultations world-wide related to chronic disorders (Assal 1999), and prescribed items for elderly people (the majority of which related to chronic illness) has more than doubled in the United Kingdom during the past twenty years (Crealy, Sturgess, McElnay & Hughes 2003; Ironside, Scheckel, Wessels, Bailey, Powers, & Seeley 2003). In 2003 chronic disease accounted for 60% of reported disease throughout the world, excluding tuberculosis, HIV/AIDS and mental health related conditions (Yach & Hawkes 2004). Clearly the addition of the excluded figures would escalate the percentage substantially. The WHO estimates the number of deaths attributable to chronic disease in 2002 at 448 per 100 000. By 2020 they expect this figure to have increased by 23% to 548 per 100 000. Other significant trends in chronic illness patterns include increases in morbidity figures (still excluding TB and HIV/AIDS), a reducing age profile and a more inclusive gender profile among people living in developing countries (Yach & Hawkes 2004). The financial burden of chronic illness has become a significant national budgetary concern. For example, the annual cost of chronic illness in the United States alone was approximately US\$700 million in the year 2000 (Norris, Glasgow, Engelgau, O'Connor, & McColloch 2003). This substantial shift toward chronic illness and co-morbidity

challenges biomedical approaches to healthcare and finds them wanting (Faber, de Castell & Bryson 2003; Grumbach 2003; Norris, *et al.* 2003):

Although a generalist⁷ approach has always been important in health care, this broader view has become imperative in the face of the changing epidemiology of illness in industrial societies. Chronic conditions, not acute ailments, are now the most common problems in health care. The acute infection caused by a single microbe that can be definitively identified and eradicated – the epitome of the reductionistic, mechanistic model of disease – has given way to chronic illnesses such as diabetes, arthritis and dementia....In chronic illness, care of the whole person is paramount (Grumbach 2003:4).

4.4.1 Chronic illness – a sociological understanding

My concern here will focus primarily on chronic illness that develops in adulthood, although many of the characteristics and concerns are to be found in persons growing up with chronic illness conditions originating at birth or in early childhood. In line with the understanding of reflexivity developed in 2.3.4 – 2.3.5 (above), differences should be expected between a child's and an adult's experience of illness precisely because illness, as distinct from disease, is a quintessentially reflexive experience. There is, however, some indication of similarities that exist, such as those suggested in Pilnick's research into interactions between patients and pharmacists in a paediatric oncology unit (Pilnick 1998, 2001, 2002). The one element that is markedly different is the impact adult-onset chronic illness can have on the life-course of the person concerned, something I shall develop further below.

Although Parsons (1951) gave some acknowledgement to chronic illness, it was really Strauss and Glaser's work in 1975 that began to focus sociological attention on the burgeoning phenomenon. Since then Arthur Kleinman (1988), Arthur Frank (1995), Michael Bury (1982), Simon Williams (various) and Gareth Williams (various) have developed thorough and substantial considerations of chronic illness from medical anthropological and sociological perspectives. Bury's consideration of chronic illness as *biographical disruption* has become a classic sociological perspective (S. Williams 2000b). Biographical disruption is descriptive of the experience of chronic *illness*, not necessarily

⁷ '...a tendency to remain broadly focused, protean, and varied in world view and activity. The generalist is interested in the big picture with all of its nuances, connections, and complexities' (Mullen 2002 in Grumbach 2004).

of chronic *disease* or *disorder*. By this I seek to distinguish the *patient's* lived experience from the 'bodily abnormality or failure to function properly' which the person – for whatever reason – does not experience as an illness. If the person is unaware, for example, of a malignant prostate tumour because it is asymptomatic, or because he may not have recognised the symptoms, then he may experience no 'biographical disruption', although he may become aware of his body in an uncomfortable way because of difficulty urinating.

Simon Williams highlights three elements of Bury's chronic illness as biographical disruption which are significant: '*disruption of taken-for-granted assumptions and behaviours... disruptions of [a person's] explanatory frameworks... [and] mobilization of resources in the face of an altered situation*' (S. Williams 2000b: 43). Bury's model still has value, but as Williams notes, it fails to account for the experiences of chronic illness which begin with birth or very early childhood, and further, it provides an inadequate explanation for the stoic experiences of chronic illness often evidenced among both the working class and old aged (illness is part of life; 'it's to be expected') (S. Williams 2000b). It also does not take into account the experience of reflexivity described by Beck (2000) which characterises late modernity, in which the body is characteristically no longer taken-for-granted (S. Williams 2000a & b). That said, the concept of *biographical disruption* remains useful in describing the experience of chronic illness which interrupts the adult life unexpectedly, and reinforces the need to view the person-in-context and not merely the biological entity.

One aspect that Bury's model does uncover is the experience – in unexpected chronic illness – of the body as demanding attention. In the 'normal' course of events we are effectively not aware of our bodies. It is only when we stub our toe, experience toothache, feel grit in our eye, or slam our fingers in a door, and so on, that we become expressly conscious of our bodies. Despite the heightened awareness of the 'body in society' noted in the discussion on health, generally our bodies escape our attention. Chronic illness changes that.

Bodily alienation begins with a radical change in the everyday, taken-for-granted relation with the body. Rather than being unreflectively lived in, the body that is in pain or that refuses to function necessarily becomes the unwelcome focus of attention. The body must be taken into account. In chronic illness this forced attention to body is ongoing. Everything else recedes into the background (Toombs 1996:5)

The very exceptional nature of the body's claim for attention creates a double problematic for the patient. They are aware of the 'not normalness' of their experience, while observers may be unaware of this experience. If the 'not-normalness' is empirically evident (for example in a deformity, discolouration, wound, etc), then the observer may have some access to the experience. Healthcare professionals are especially vulnerable to the problem this presents:

A further problem with communication in the clinical context occurs because subjective experience is essentially unshareable. As Scarry (1985) notes with respect to sensations such as pain:

'For the person whose experience it is, it is "effortlessly" grasped (that is, even with the most heroic effort it cannot not be grasped); while for the person outside the sufferer's body, what is "effortless" is not grasping it (it is easy to remain wholly unaware of its existence; even with effort, one may remain in doubt about its existence or retain the astonishing freedom of denying its existence. . .)' (Toombs 1996:5).

When healthcare professionals' knowledge of a disorder is limited to that of 'disease' (the 'reconfiguration of the patient's illness problems as narrow technical issues'), then this intensifies the gap between the experience of illness and the perception of the healer (Faber, de Castell & Bryson 2003). This gap is exacerbated if the healthcare professional's diagnosis (her construction of the condition) is incorrect, as the assumptions are thus even further removed from the illness experience of the patient.

Like other chronically ill patients, on many occasions I have found that medical professionals find it hard to trust my personal experience of multiple sclerosis. Some have insisted that my perception of bodily change is incorrect (because no quantitative measurement records it); others have agreed with my assessment but only after a clinical test or examination has "confirmed" it. If medical professionals deny a patient's experience, then meaningful communication between them is impossible (Toombs 1996:6).

Still within the context of unexpected illness, biographical disruption involves more than the 'no longer taken-for-grantedness' of the body, (which may well occur with aging), it also includes the *disruption of a person's explanatory frameworks*. Ultimate questions arise (such as 'why me?'), which can reach to the foundations of a person's life. These are questions for which biomedicine's reductive philosophical underpinnings provide inadequate responses (S. Williams 2000b:43). The disruption is also practical: *resources must be mobilised*. Such resources include time, people and economic resources, which (with the exception perhaps of medical insurance and specialised insurance against 'dread diseases') usually have to be diverted from elsewhere, and so are disruptive of plans and life in general. Recognising chronic illness (or, indeed, even in some cases shorter term illness or

injury which can produce similar disruptions) as biographical disruption, makes the recognition of the influence of the wider context of illness unavoidable.

Bury's recognition of the involvement of meaning – both as consequence and significance – is implicit in the idea of the disruption of explanatory frameworks. *Consequences* would involve changes in work, social life and home, as well as costs which evolve from these, while significance relates more to the views of society (S. Williams 2000b:44). These may influence the way the chronically ill person responds to the illness, and are closely connected to the understanding of reflexivity; and structural enablements and constraints; noted earlier (2.3.5. above). It is in this connection with the critical realist understanding of reflexivity and personal identity that one of the weaknesses of Bury's model of biographical disruptions shows.

Arthur Frank's work (1995) has a slightly different purpose, seeking primarily to consider how seriously ill people can and do make use of narrative to make sense of (to understand) the impact of such illness on their person and lives. Frank, himself living in remission from cancer, refers to people living with serious chronic illness as people who live in the 'demilitarized zone' between being cured and yet living with illness (1995:9). Such people are members of the 'remission society' (1995:8). Frank's account is congruent with the understanding of reflexivity with which this chapter began, and bears remarkable similarity to the insights provided by Bury. This is well captured in the opening paragraph of *The Wounded Storyteller*:

"The destination and map I used to navigate before were no longer useful." These words were in a letter describing chronic fatigue syndrome. Judith Zaruches wrote of how, after an illness that is never really finished, she "needed...to think differently and construct new perceptions of my relationship to the world." Serious illness is a loss of the "destination and map" that had previously guided the ill person's life: ill people have to learn "to think differently". They learn by hearing themselves tell their stories, absorbing others' reactions, and experiencing their stories being shared (Frank 1995:1).

As with Bury's account of chronic illness, Frank too identifies the 'silence' of chronic illness, and the way the failure of healthcare professionals to recognise the patient's experience, often becomes a characteristic of living in the 'demilitarized zone' – an image which accords well with the notion of fighting an illness (Frank 1995). Frank's project suggests that people with chronic illness respond to this experience in different ways, but essentially

through narrative, which is the embodied persons' way of accounting for chronic illness and developing a new 'destination and map'. Illness narratives can be generally categorised into three: restitution, chaos and quest (Frank 1995). The *restitution narrative* follows the essential plot line 'Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again' (Frank 1995:77). Such a narrative is preferred by society as it accords with responsibility, health as a gift and similar late modern discourses of health (Frank 1995). Such stories appear as a denial of illness, and yet are not, but they are an attempt to 'outdistance mortality by rendering illness transitory' (Frank 1995:115). The second narrative is the *chaos narrative*. This represents the opposite of the preferred social narrative. Here there is no hope of getting better, the life-map is lost and life's remaining journey is confused, directionless and unpredictable. Such narrative accounts are difficult for healthcare practitioners to hear, because they challenge the whole professional project of healthcare (Frank 1995). The third narrative suggested by Frank is the *quest narrative*. Such narratives confront illness and seek to gain as much understanding about life and meaning as is possible. This is not a wallowing in self-pity, or a pathological search for information about a disorder (although it may involve a determination to discover information not controlled by the healthcare profession). Illness is not denied, nor is mortality, but illness becomes an opportunity for intentional reflexivity ⁸.

Essentially, all three narratives simply represent ways in which people experience the phenomenon of illness-without-a-cure. These are part of what Charmaz calls 'normalizing illness and regimen' (2000:283). Such normalizing differs from person to person, in some cases 'scaling back' on life, while others embark on new challenges and yet others 'struggle...to make life manageable so a valued future is possible' (Charmaz 2000:283). Generally normalizing is aimed at reducing the social impact of their illness, attempts to 'limit disruptions' and facilitate continued social interaction for as long as possible. Normalizing is not the same as 'managing' illness, but certainly involves management of illness. But management of chronic illness becomes an ongoing process of negotiation, not control. Charmaz's observations are significant in this respect:

[People managing their illness] become innovators. To do so they listen to their bodies and stay in tune with them in ways that they had not and in ways that Western culture discourages. They may make use of indigenous support groups, newsletters, and computer networks

⁸ Note Bury's caution with respect to the sociological consideration of illness narratives: '...narratives take many forms, have many uses and serve many purposes, for individuals and for social groups. In these circumstances links between chronic illness and self-identity are neither self evident or unproblematic. If they were, the need for an interpretative act on the part of the investigator would be redundant. The desire to represent the 'patients' viewpoint' does not mean that an evaluative and contextual approach to patient narratives is not required. Quite the reverse.' (Bury 2001:281)

independent of professionals.... Some chronically ill people become so adept at monitoring and managing their illness that they break through textbook definitions, construct new ways of living with their illness; but medical professionals may not welcome their innovations... Consequently, ill people's strategies for managing illness can require strategies for effective negotiations with professionals to minimize conflict (2000: 283 – 284).

Charmaz goes on to argue that healthcare for chronic illness is not merely a matter of the acute care model extended for some time. Chronic illness care requires a new, integrated care model, something which the current trend in 'managed care' militates against by 'curtailing and cutting services' (Charmaz 2000:287).

In the context of chronic illness the idea of 'effective negotiations with professionals' involves negotiation around treatment regimens: regimens which frequently involve medication. The pharmacist as 'custodian of medicine' (SAPC 2004:2) thus becomes a central figure in the therapeutic process, and in negotiations with the patient with respect to medicine-taking (Chapters 5 & 6, below). Medicine-taking decisions, especially by people living with chronic illness, are a source of significant concern to healthcare professionals and have resulted in a substantial and wide ranging research output. As the WHO note:

...empirical studies have consistently found that levels of compliance or adherence are often far from optimal Because the burden of illness in the population has shifted toward chronic diseases, the problem of poor adherence is of major concern to all stakeholders in the health care system. This is because the risk of poor adherence increases with the duration and complexity of treatment regimens and both long duration and complex treatment are inherent to chronic illnesses (WHO 2003:135).

In the following chapter I offer a consideration of the debate around medicine-taking decisions (and actions) framed around the terms (and the underlying perspectives): *compliance, adherence and concordance*.

Chapter 5: (Non-) compliant, (Non-) adherent: Medicine-taking Decisions in Chronic Illness

‘The physician must not only be prepared to do what is right himself, but also to make the patient ... cooperate’ (Hippocrates in Turner & Hecht 2001:1006)



Figure 5-1: <http://www.antipsychiatry.org/drsmith1.htm>

5.1 Introduction

The previous chapter considered the complex interrelationship between disease/illness/sickness, and particularly how this interrelationship plays out in chronic illness. The discussion around disease/illness reflects what may appear as a perplexing, even oppositional, relationship between healthcare professionals and people seeking healthcare¹ (Loewe, Schwartzman, Freeman, Quinn & Zuckerman 1998). It also suggests that this uneasy relationship is rooted in asymmetry of power and different epistemological perspectives. As Bissell, May and Noyce note with respect to studies of medicine-taking decisions among diabetics:

The differences in the types of knowledge upon which health professionals and diabetics base their assessments can lead to overt conflicts in which physicians accuse diabetic people [of being irresponsible], when the latter are convinced such assertions are unjust (2004: 853).

At times healthcare professionals appear as oppressors to be resisted, while in the same moment as sources of help. Medicines are at times portrayed in public debate as life-saving and ‘toxic’ (Scherman & Löwhagen 2003). People pay (either directly or through medical aid or insurance schemes) huge sums of money for advice and treatment which they then

¹ I realise that in some cases people do not seek healthcare, but are forced by society to ‘receive’ such ‘care’ (for example in treatment of infants, of people deemed to have ‘mental illness’ and perhaps those being kept alive by life-support systems while comatose). It is not possible to attend to the hugely complex debates around such instances within the confines of this study, which is concerned with those who choose to seek healthcare.

ignore or abuse. In other cases people will seek assistance from a range of healthcare providers, often without telling one of the treatment they are receiving from another. One set of researchers argue that the problem centres around medicines themselves: ‘...lay beliefs about medicine taking provided an insightful explanation for the behaviour that many professionals find bewildering; they concluded that lay people do not view medicine as something to be taken ‘as prescribed’ but rather as a resource for use as they see fit’ (Blaxter & Britten 1996, in Pound, Britten, Morgan, Yardley, Pope, Daker-White, & Campbell 2005:134).

In much of the literature of medicine, pharmacy and health-related sociology, this debate is framed within the discourses of *compliance* / *non-compliance* or *adherence* / *non-adherence*. Each of these terms (and the discourses of which they are a part) seek to describe, understand, label, or promote an approach to the way ‘patients’ make decisions about therapeutic regimens. Such regimens may include a wide range of components, including – but not limited to – surgery, physiotherapy, psychotherapy, radiotherapy, diet, exercise, and pharmacotherapy. While frequently more than one of these (or other) elements will be prescribed, the primary concern of this study is with the last of the examples: medicines.

In the sections that follow I shall use a critical overview of the extensive debate around medicine-taking decisions and behaviour to identify the values, attitudes and ideological assumptions that underpin the primary discourses of medicine-taking. I will then suggest that ‘concordance’, the process proposed by the Royal Pharmaceutical Society of Great Britain (Cox, Stevenson, Britten & Dundar 2002; Bissell, May & Noyce 2003), is most appropriate for supporting optimal medicine-taking decisions by people living with chronic illness, and is congruent with an approach to pharmacy practice built on a revised understanding of pharmaceutical care which will be proposed in Chapter 6.

5.1.1 *Medicine-taking as a healthcare concern*

An indication of the extent to which medicine-taking decisions have become a global concern is reflected in the volume of the related literature. Cox *et al.* (2002:1) identified 11,801 articles published between 1991 and 2000 relating to only one component of medicine-taking literature, namely communication between healthcare professionals and patients. Vermeire *et al.* (2001) offer a conservative estimate of the costs of ‘medical non-compliance’ (which ironically refers to patient non-compliance with medical directives) in

the United States at US\$100 million a year. Kleemput, Kesterloot and DeGeest provide one estimate as high as US\$13.35 *billion* (2002:80). The WHO report on adherence related health concerns notes that:

...in China, the Gambia and the Seychelles, only 43%, 27% and 26%, respectively, of patients with hypertension adhere to their antihypertensive medication regimen ... In developed countries, such as the United States, only 51% of the patients treated for hypertension adhere to the prescribed treatment.... Data on patients with depression reveal that between 40% and 70% adhere to antidepressant therapies.... In Australia, only 43% of the patients with asthma take their medication as prescribed all the time and only 28% use prescribed preventive medication.... In the treatment of HIV and AIDS, adherence to antiretroviral agents varies between 37% and 83% depending on the drug under study ... and the demographic characteristics of patient populations.... This represents a tremendous challenge to population health efforts where success is determined primarily by adherence to long-term therapies (WHO 2003:7).

Rietveld and Koomen summarise the therapeutic concerns held by healthcare professionals:

Inappropriate medication compliance is a classic problem in healthcare and is considered to be associated with medical complications, pathology that does not improve with treatment, negative prognosis and an unfavorable [*sic*] patient-physician relationship.... Despite numerous attempts to improve medication compliance over a period of 40 years, these efforts have often been unsuccessful (2002:622).

Fundamental to the problems noted above, and the discussion below, are the different perspectives on decisions about therapeutic options (Bissell *et al.* 2003; Pound *et al.* 2005). Crudely these perspectives are often characterised as the rational, informed advice of the healthcare professional (HCP), against the irrational, uninformed and often careless lay perspective of the patient and her/his caregivers. This study is primarily concerned with medicines and medicine-taking, but clearly these cannot be separated from more general therapeutic decisions. At issue is not a theoretical discussion, but the very real consequences for patient, HCP and society, of taking or not taking medication. According to Chewning and Sleath there is:

...growing documentation of negative health outcomes and increased health care utilization associated with poor medication management by clients.... a study of 315 elderly patients admitted consecutively to an acute care hospital, ... found that 28% of the admissions were drug-related, 36 due to non-compliance (11.4%) and 53 due to adverse drug reactions (16.8%). One hundred three patients had a history of noncompliance (32.7%) (Chewning & Sleath 1996:389).

One substantial set of ‘real consequences’ broached in Chewning and Sleath’s (1996) reference above, are the unintended consequences of medication use, or Adverse Drug Reactions (ADR). Pound *et al.* (2005) note how ADRs² form a significant and very influential part of patient decision-making with regard to therapeutic decisions. General practitioner Iona Heath agrees, arguing that:

History suggests that every generation of doctors looks back complacently at the ignorance of its predecessors while overestimating the robustness and longevity of its own knowledge. Many patients seem wiser and more cautious, apparently fully aware of the evolutionary process whereby today's miracle cure becomes tomorrow's killer. The recent research on the risks of hormone replacement therapy provides only the latest example of the shifting sands of medical knowledge (Heath 2003: HTML Document).

Patients and HCPs are involved in constant risk-benefit analyses when it comes to medication use, and as the ones who have to live with the consequences of the choices, patients’ perspectives often differ from those of HCPs (Donovan & Blake 1992; Pound *et al.* 2005). Bissell *et al.* illustrate this with respect to people living with diabetes:

... Drummond and Mason (1990) have described that the goals of treatment from the medical perspective are largely concerned with maintaining blood glucose levels within an acceptable band. However, people with diabetes often identify a much broad [sic] set of constraints which influence treatment, including work, housing, finance, family, and emotional factors.... Such factors can have significant bearings on patients’ decisions to integrate the treatment regimen into their daily lives. Peyrot, McMurry, and Hedges (1987) describe how the decision to adhere to ‘tight’ or ‘loose’ control of blood sugar levels is a personal decision based on the desire to control the effects of the illness and the treatment on sufferers’ lives (Bissell *et al.* 2004:852).

5.1.2 (Non-) compliance: aetiology and symptoms

‘Compliance’ is defined as ‘... “the extent to which a person’s behavior (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical or health advice”...’ (Haynes, Taylor, & Sackett 1979 in Conrad 1985:29). ‘Compliance’ (also termed ‘medical compliance’ and ‘therapeutic compliance’) is, however, inseparable from its converse ‘non-compliance’. Our use of language about an object (or action) is not independent of other objects or actions. We ‘refer to objects (whether material or abstract)... by making contrasts with others – by differentiation. A particular term takes on meaning only through its relationship to others...’ (Sayer 1992:55 – 56). Labelling a

² In the usage of the Faculty of Pharmacy in which this study was conducted ADRs are included in Drug Related Problems (DRPs) (Mansoor 2003; Wrench 2004).

patient 'compliant' is done by making a contrast with patient 'non-compliance', and as was intimated in the previous section, it is 'non-compliance' that is more pervasive both in the literature and in practice (Conrad 1985). Compliance discourse is rooted in the biomedical perspective, according to which:

...human pain and suffering are caused by disease processes. Disease activity is measured by judgments of trained physicians and by physiological measures, including blood chemistry and radiographic evidence of pathology. The purpose of medicine is to find disease pathology and to fix it. For problems such as high blood pressure, for example, the physician's task is to diagnose the problem and administer a medicine that will make blood pressure normal. The measure of success is a blood pressure reading that falls within a defined range of normality. Treatment decisions involve the selection of the alternative that is indicated, and patient participation in decision making is regarded as unnecessary. Patients who do not use the indicated treatment are nonadherent [noncompliant]. When the treatment fails to obtain the expected benefit, a common explanation is patient nonadherence [noncompliant] (Sieber & Kaplan 2000:234s).

The medical use of 'compliance' originates from the work of Sackett and Haynes in 1976 (Lerner 1997:1423) and is frequently associated with medical concerns arising from the first use of modern pharmaceutical antibiotics (Trostle 1988). However, as the prefacing quotation from Hippocrates suggests, the referent to which 'compliance/non-compliance' points is not new, but is reflected in the history of interactions between those granted healthcare authority and those in need of such care. Indeed Trostle provides a cogent argument that compliance is best understood 'by referring to cultural beliefs in curative substances and the history of the profession of medicine, as much as the efficacy of pharmaceuticals' (1988:1301). The connection between culture, religion and healthcare and the influence of 'illness as sin' lingers in the ideological shadows of compliance discourse (Trostle 1988). It is these ideological shadows that are central to the sociological critique of the discourse of compliance³.

The central critique of compliance discourse is that it serves to locate treatment failure in the patient, and construes the patient as passive at best, or irrational and deviant at worst (Conrad 1985; Lerner 1997; Trostle 1988; Playle & Keeley 1998; WHO 2003; Tabor & Lopez 2004). 'Deviance' suggests behaviour that differs from the norm, and yet Donovan

³ 'Ideology' is used as described in the Glossary. 'Compliance' will be used to refer to the discourse which supports 'non-compliance', as the one is implied by the other and share the same ideological and professional values.

and Blake (1992) point out, research on compliance suggests that non-compliance rates are higher than those for compliance, making it difficult to consider non-compliance as anything but normal behaviour. Trostle (1988) and Playle & Keeley (1998) argue that it is misleading to regard compliance discourse simply as facilitating a description of behaviour. This reductive tendency inherent in compliance discourse focuses on patient behaviour. Such a focus ignores the role of meaning in any social action or practice (Sayer 1992), such as the medicine-taking practice of people living with chronic illness (or indeed even acute conditions, such as in the use of antibiotics prescribed for *viral* infections such as influenza). Trostle argues that compliance is:

better approached as an ideology supporting the authority of medical professionals.... [which] reveals [that in] the medical profession's worldview the problem lies in patients' behavior [*sic*] or in doctor/patient interaction, the solution lies in patient education, behavioral [*sic*] reinforcements, and better doctor/patient communication (1988:1299).

Ten years later, Playle and Keeley maintained that little had changed. Compliance ideology:

consists of professional beliefs about the 'appropriate' behaviour of patients, viewing non-compliance as deviant and irrational in the light of professional rationality. It also tends to assume that on the whole patients are passive recipients of treatment. Such an ideology has been the basis of various research strategies and potentially coercive interventions, that whilst appearing clinically appropriate, serve to justify and reinforce professional authority and power (1998:309).

Echoing these views Bissell, May and Noyce contend that 'compliance' provides 'a framework for doctors to express their ideas about how patients ought to behave' and that such a model offers 'clear justifications for attributing blame when patients' actions do not match the expectations placed on them by health professionals' (2004:851). Incongruously, compliance discourse construes the patient as both passive and at the same time responsible for failure (Tabor & Lopez 2004). This agential oxymoron is rooted in the problems inherent in the biomedical, disease-focussed approach to practitioner-patient interactions noted above (Sieber & Kaplan 2000 and 2.2.1; 4.3.2 & 4.4.1).

Charles, Gafni, and Whelan (1999) argue that compliance discourse is rooted in pre-1980's medicine, which was dominated by acute disorders, most of which had agreed 'single best treatments' with which HCPs were familiar. In addition, because of their membership of an altruistic profession, HCPs were regarded as best suited to take the sole role in making treatment decisions (1999:652). This easily permitted the 'doctor knows best' paternalism which is characteristic of compliance discourse. From the 1980's on, however, many of

these assumptions have been subjected to challenge. New knowledge challenged many of the single-cause theories. The increasing incidence of complex chronic disorders, characterised by a range of causal factors, overtook simple disorders. Awareness increased of the unintended consequences of medication, including side-effects and iatrogenic disorders. In addition the rise of managed health care; and increased awareness of medical errors and concomitant litigation; influenced the development of 'informed consent' legislation (Charles *et al.* 1999: 653). Out of these circumstances emerged a growing critique of compliance discourse as an inadequate approach to describing and understanding patient medicine-taking behaviour. With respect to chronic illness, the critique emphasised the failure of compliance discourse to recognise patient knowledge and beliefs in the 'diagnosis' and therapeutic decision-making (Bissell *et al.* 2004; Theunissen, de Ridder, Bensing, Rutten, 2003).

Despite proposing a 'complex systems approach' emphasising a 'holistic approach', Rietveld and Koomen (2002:621; 628) reflect how little credence is granted to the value of patient understanding, contrasting HCP 'knowledge' with patient 'beliefs'. With respect to medication they conclude that '...patients' beliefs that medication is helpful or necessary is [sic] crucial for good medication compliance, but *these perceptions are often disturbed by irrational beliefs or poor estimations of the advantages and disadvantages of the medication*' (2002:627 Italics added). The implication is that the HCP's beliefs are rational and sound, while patients' questions or understanding regarding medicine are irrational and poor, even if 'educated' about the medicines (in some cases especially if educated about medication – 2002:624). In this view, patient decisions at variance from the HCP, can only be based on ignorance or deliberate disobedience. For example, Tabor and Lopez suggest that patients may make medicine-taking decisions based on the desire to 'retaliate through nonadherence' (2004:169). Such a perspective can only be predicated on the assumption that *illness* understanding and decisions that differ from the HCP's are inherently 'irrational and poor'. These assumptions make it unlikely that patient experience of medication will be granted credence in therapeutic decisions without the support of 'objective data'.

A further consequence of the paternalism inherent in biomedical compliance discourse is the emphasis on education in 'combating' non-compliance. This emphasis often reflects a deficit view of the patient, and asserts the assumed authoritative legitimacy of the HCP's

action couched in the rational versus irrational comparison. This is noted by Tabor and Lopez (2004) and is clearly apparent in one of the recommendations offered by Stotland (2003):

Before explaining diagnosis and treatment, tell the patient that you don't expect all the information to sink in at this visit. Offer written material at no more than a sixth grade reading level, unless you are sure the patient is able to comprehend more sophisticated communications (2003:118).

The complexity of factors underlying medicine-taking decisions is underlined by the considerable evidence that simply 'correcting' patient (mis-)understandings through education does not seem to produce a 'compliant' patient (Rietveld & Koomen 2002; Stevenson, Britten, Barry, Bradley, & Barber 2000; Theunissen *et al.* 2003). If patient knowledge and experience is disregarded in therapeutic decisions, it becomes more likely that the patient will not be open with the HCP about their medicine-taking, and the therapeutic relationship between HCP and patient will be damaged (Stotland 2003; Theunissen, *et al.* 2003; Pound *et al.* 2005). This leads to the very real possibility that treatment will be prescribed based on incorrect assumptions by the HCP (Rietveld & Koomen 2002).

In effect compliance discourse fails to recognise patient agency. This implies that strategies to bring patient medicine-taking decisions into closer alignment with the regimen determined by the HCP(s), are based on the agency of the HCP alone. As Rietveld and Koomen (2002), Bissell *et al.* (2003), Theunissen *et al.* (2003), and Scherman and Löwerhagen (2004) contend, and the WHO (2003) figures (above) support, attempts based on compliance models have been unsuccessful in bringing patient medicine-taking decisions into alignment with HCP prescriptions. Ironically, it would seem that despite the substantial evidence of its failure, many operating within biomedical discourse continue trying to fine-tune the model (Coons 2001; Merck 2005) without adequately questioning the underlying assumptions:

Many compliance programmes have focussed on practical difficulties in medicine taking. However, the differences between the patient's beliefs and understanding of the diagnosis and proposed treatment, and those of the health professional are crucially important. *The health professional has a set of beliefs about the appropriateness of particular medicines, and about how they should be used based on a biomedical model. These beliefs are shaped by the content of professional training, and on the evidence from a large body of scientific research.* The patient has a different, but equally cogent and coherent set of ideas about their own illness [sic],

medicines in general and their medicines in particular. These are based on their own preferences, priorities, beliefs, attitudes and life experience (Fish 2004: HTML Document - *Italics added*).

Patients (and HCPs) can, and do, make decisions based on understandings that are not congruent with the way the medication is understood to act. The consequences of such decisions may negatively affect the effectiveness of medications, and impact negatively on the health of the patient. However, in chronic illness especially, patient experience of medicines may lead to medicine-taking decisions based on practical risk-benefit analyses, related to quality-of-life choices over possible therapeutic advantages (Donovan & Blake 1992). In some cases, especially with respect to women, social factors and the influence of medication side-effects on relationships, outweigh professional medical advice (Pound *et al.* 2005). This is consistent with the understanding of illness versus disease noted in the previous chapter. Such decision-making choices are not easily dismissed as ‘irrational’, but constitute a reasoned decision-making process based on risk-benefit analyses that use different data to that of the HCP (Donovan & Blake 1992).

My concern is not to insist that patients’ knowledge replace the HCP’s knowledge. There is, however, common recognition that patient ‘beliefs’ and experience are significant among the range of influences on medicine-taking decisions. Their experience and knowing cannot be construed as deviant simply because they present qualitatively different data from that used by the HCP. More significantly, even should a patient’s reasoning be open to challenge, once the patient is out of the consulting context, her knowing will inform her decisions. If for no other reasons than these, patients’ experiences of their illness and medication must be given credence in diagnostic and therapeutic decisions (see below 5.1.4):

It is clear that the term compliance can no longer be simply taken for granted. A paternalistic approach in this matter should be avoided because the doctor-patient relationship, communication and shared decision-making are important factors affecting compliance. Patients’ health beliefs and the patient perspective should be incorporated in the doctor-patient encounter (Vermeire, Hearnshaw, Van Royen, & Denekens 2001:340).

5.1.3 Adherence: compliance in patient-centred clothing?

Vermeire *et al.* (2001) call for a shift away from ‘compliance’ to the term ‘adherence’. Adherence, as with ‘compliance’, is inseparable from its obverse, and I shall use ‘adherence’ (as including non-adherence) to refer to the underlying discourse.

The introduction of the term adherence was a deliberate attempt to move away from compliance discourse and its associated paternalism: ‘It is suggested that the term adherence reduces attribution of greater power to the doctor in the doctor-patient relationship which the term compliance brings ...’ (Vermeire *et al.* 2001:333). This position is supported by the WHO, who also critical of compliance discourse, define adherence as ‘the extent to which a person’s behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider’ (WHO 2003:3). While at first glance this definition differs very little from the definition of ‘compliance’ noted above (5.1.2), the key words that point to a significant shift are ‘agreed recommendations’. This is rooted in an understanding that

... the relationship between the patient and the health care provider (be it physician, nurse or other health practitioner) *must be a partnership that draws on the abilities of each*. The literature has identified the quality of the treatment relationship as being an important determinant of adherence. *Effective treatment relationships are characterized by an atmosphere in which alternative therapeutic means are explored, the regimen is negotiated, adherence is discussed, and follow-up is planned* (WHO 2003:3 Italics added).

Despite this attempt to introduce a new term (and an underlying approach), Cox *et al.* (2001), Vermeire *et al.* (2001), and Bissell *et al.* (2003) all reflect that in many cases neither practice nor the literature, make a real distinction in the usage of the two terms. The problem remains the focus on patient adherence to / compliance with medical instructions (Troostle 1988). This is exemplified in proposals for pharmacists’ involvement in improved medicine adherence proposed by Tabor and Lopez (who use ‘compliance’ / ‘adherence’ interchangeably) where the discourse remains that of control and authority:

After careful patient assessment, an individualized plan can be developed and implemented. Furthermore, *persistent and consistent monitoring and reassessment leads to positive rewards of improved medication compliance and patient health*. Patient counseling [*sic*] and communication are vital to a successful pharmaceutical care plan. It is important that the *clinician be familiar with useful strategies for specific patient populations and disease states*. Pharmacists are often in a setting that enables them to *assume responsibility for patient medication compliance, and they can*

therefore improve humanistic, clinical, and economic patient outcomes
(Tabor & Lopez 2004:179 Italics added).

No mention of partnership or negotiation is evident in this description of the role of the pharmacist. Instead pharmacists are reminded that it is ‘...important to identify specific populations or disease states that are more prone to compliance problems’ (2004:179). This identification of ‘the problem’ in either the population or disease state, leads easily to language which construes ‘non-adherence’ as deviant. For example, Tabor and Lopez argue that:

Nonadherence can be viewed as a behavioral [sic] disorder, sharing many of the same characteristics as a medical disorder. Like a disease, numerous risk factors for nonadherence have been identified and may be social, economic, medical, or behavioral. Risk factors can relate to the disease, the patient, or the drug regimen. Nonadherence can be assessed and monitored through a variety of direct and indirect methods, and there are effective strategies available to treat poor compliance. Morbidity and mortality frequently are end results of nonadherence, which tends to have a variable course. Therefore, patients should be periodically reevaluated [sic] and reassessed for adherence (2004:168).

The International Pharmaceutical Federation (FIP) argues that patients do not make decisions to ignore HCP instructions simply because they are ‘deviant’, but subject to their experience of a range of structural constraints in a complex world (FIP 2003). Trostle contends that non-compliance must be understood as ‘an unavoidable by product [sic] of collisions between the clinical world and other competing worlds of work, play, friendship, and family life’ (1988:1305). Any approach to medicine-taking decisions must thus consider issues of both structure and agency. *Concordance* has been proposed as just such an approach to describing and working with the realities of medicine-taking decisions.

5.1.4 Concordance – calling attention to a therapeutic alliance

Concordance is based on the notion that the work of the prescriber and patient in the consultation is a negotiation between equals and the aim is therefore a therapeutic alliance between them. This alliance, may, in the end, include an agreement to differ. Its strength lies in a new assumption of respect for the patient’s agenda and the creation of openness in the relationship, so that both doctor and patient together can proceed on the basis of reality and not of misunderstanding, distrust and concealment (Working Party, 1997 in Bissell *et al.* 2004:852).

The concept of concordance reflects a different approach to considering the process through which therapeutic decisions are made. Unlike compliance or adherence, it refers not to the behaviour of the patient, but places emphasis on the *relationship* and *process* in

which an alliance between HCP and patient is reached with respect to therapeutic decisions. Despite examples in recent literature, one cannot speak of a ‘concordant’ or ‘non-concordant’ patient. With its linguistic root in the French concept of ‘harmony’, not obedience, concordance refers to an agreement between ideas, institutions or people (Collins English Dictionary 1979). Concordance remains a process concerned with optimal (‘degree, amount, or compromise that produces the best possible result’ – Collins English Dictionary 1979) outcomes of therapy, but does not assume that these automatically imply the dutiful obedience of the patient to the wise counsel of the practitioner.

Like compliance and adherence, concordance is contested and complex – but it is not simply another term for compliance. Or is it? Heath (2003), Jones (2003), and Armstrong (2005) each raise doubts about the meaning and value of ‘concordance’. Heath argues that it is simply ‘a wolf in sheep’s clothing’ and does not go far enough in challenging medical control. Jones (2003:819) is concerned that theory has degenerated into the subversive practice of ‘a more gift wrapped version of compliance’. Armstrong contends that concordance was always subversive:

...let us not get starry-eyed about concordance. The main goal of many (most?) of its proponents is to get patients to take their medicines as directed, or at least not waste them. Arguments in favour of concordance are consistently embedded in discussion of the compliance ‘problem’ (which is of course a problem for paternalistic medicine, not for patients who simply decide for themselves whether to take their medicine as directed or not). Look at the publications on the ‘Medicines Partnership: from compliance to concordance’ website (<http://www.medicines-partnership.org>) or note the telling title of a recent report from the UK House of Commons All-party Pharmacy Group, ‘Concordance and wasted medicines’. Concordance is fast becoming the acceptable face of compliance: the goals remain the same but the technique is more subtle as patients are recruited to direct themselves in medicine-taking (Armstrong 2005:26).

Stevenson and Scambler (2005b) reject Armstrong’s thorough-going scepticism. However, they do express a concern that *possibly* the ‘move from compliance to concordance – one which is in part ‘political’ or rhetorical – may in practice result in a shift from open strategic action to concealed strategic action, and significantly to systematically distorted communication’ (2005b:30). The core of both Armstrong’s (2005) and Stevenson and Scambler’s (2005a & b) arguments, is that the healthcare profession cannot be trusted to abandon its position of power, and patients do not always seek, or enjoy, participation in decision making.

With these comments as caveats to warn against too naive a promotion of concordance as: the ‘new way to define the process of successful prescribing and medicine taking, based on partnership’ (Fish 2004: HTML Document), I argue that concordance nonetheless offers a helpful model for healthcare professionals to consider in seeking a therapeutic alliance with patients with respect to optimal medicine-taking decisions. Fundamental to the value of concordance is its *epistemological* recognition that (except in the case of a comatose patient) it is the patient’s knowing that will decide how and when medication will be used (Bissell 2003). This recognition facilitates more informed decisions by both HCPs and patients (Sieber & Kaplan 2000), and creates the potential for more open relationships between HCPs and patients:

Doctors say that not taking drugs means poorer health outcomes, but patients argue that only they can know what works for them and what doesn't. Bridging the gap between the agendas of patients and doctors changed the emphasis from the authoritarian concept of compliance to the more inclusive concept of concordance. Concordance means shared decision making and arriving at an agreement that respects the wishes and beliefs of the patient. What it should not be is a more gift wrapped version of compliance (Jones 2003:819).

One of the central themes of concordance is the creation of a ‘healthcare relationship based on respect, within a blame-free environment’, which sheds the moral judgement implicit in compliance discourse (Bissell *et al.* 2003:500). In this, concordance is well supported by the biopsychosocial (BPSP) approach proposed by Borrell-Carrió *et al.* (2004) noted above (2.2.2.3). It is important to note that concordance does not remove responsibility from the patient, but it calls for an honest sharing of responsibility between HCP and patient – a point cogently argued by Thomasama (1983). Concordance recognises the structure / agency relationship of both HCP and patient, and acknowledges that not all patient (or HCP) decisions are made without constraints. By contrast, the compliance model has no facility to recognise anything other than the apportioning of blame, or the judgement of inadequacy where patient decisions or actions differ from HCP instructions (Bissell *et al.* 2003).

Concordance also foregrounds the recognition that patient and HCP decisions have similar, but not identical goals. The goal of the HCP may be ‘to treat symptoms or cure disease, ...[while]... for the patient these are but components of a spectrum of other life circumstances’ (Bond 2003:497). Crucially, prescribing decisions are often made forgetting that even people living with chronic illness spend a small portion of their time as

‘patients’ (Conrad 1985). Further, in chronic illness people often ‘do not view medicine as something to be taken “as prescribed” but rather as a resource for use as they see fit’ (Pound *et al.* 2005:135). Conrad illustrates this from the medicine-taking decisions of people living with epilepsy.

[Some patients] ...spoke often of how they changed the dose or regimen of medication in an effort to reduce the risk of having a seizure, particularly during ‘high stress’ situations. Several respondents who were students said they take extra medications during exam periods or when they stay up late studying. A law student who had not taken his medicine for 6 months took some before his law school exams: “I think it increases the chances [seizures] won’t happen”. A woman who often participated in horse shows said she “usually didn’t pay attention” to her medication practice but takes extra when she doesn’t get the six to eight hours sleep she requires: I’ll wake up and take two capsules instead of one. . . and I’ll generally take it like when we’re going to horse shows. I’ll take it pretty consistently”. Such uses of medication are common ways of trying to forestall ‘possible trouble’ (1985:35).

What concordance seeks to do, is to permit more open acknowledgement of these differing goals, and in the light of this acknowledgement, to create an environment in which the patient and HCP may reach an agreement about how to proceed with therapeutic decisions and regimens. Concordance also seeks to facilitate open discussion regarding the patient’s concerns regarding ADRs / DRPs, as they appear in her/his life. Such discussions permit further negotiation about medication options and dosage: negotiation in which both HCP and patient understand what is happening (Weiss & Britten 2003). Such negotiation may enhance the possibility of optimal therapeutic decisions, including the reduction of over-prescription of medication and the facilitation of more appropriate prescription. Pound *et al.* (2005) illustrate the way patients with chronic conditions weigh ADRs very heavily in medicine-taking decisions. Quality of life choices (which are primarily decisions of agency) often take greater precedence than the possible extension of life offered by medications. HIV/AIDS patients reflect this in a way that challenges biomedical perceptions of rationality and compliance rooted in a disease discourse, precisely because the quality of life choices with which such patients are confronted, often prove to outweigh the DRPs associated with anti-retrovirals (Pound *et al.* 2005).

It is the very incurability of chronic illness which highlights the *irrationality* of compliance discourse, in which those who prescribe (both therapy and behaviour) do not know the experience of the patient – although they may know of it (Stevenson *et al.* 2002).

Therapeutic decisions in chronic illness require balancing the algorithms of professional healthcare, with the needs and experience of the individual sick person. As Sieber and Kaplan argue ‘blind adherence to medical advice may help medical research answer an isolated question, but that understanding patients’ needs and respecting their ability to make informed decisions should be considered in clinical care’ (2000:233s).

This perspective is well articulated by the primary organisation involved in the promotion of concordance, the Royal Pharmaceutical Society of Great Britain (RPS):

The intention is to assist the patient to make as informed a choice as possible about the diagnosis and treatment, about benefit and risk and to take full part in a therapeutic alliance. Although reciprocal, this is an alliance in which the most important decisions are agreed to be those that are made by the patient (RPS 1997 in Cox, Stevenson, Britten & Dunder 2002:10).

Such a perspective on the clinical encounter (with any HCP) is congruent with the understanding of ‘professionalism’ proposed by Evetts (2003:397). This centres on ‘dealing with risk, with risk assessment and, through the use of expert knowledge, enabling customers or clients to deal with uncertainty’ (6.2.2 below). This understanding of concordance is congruent with the observation by Stevenson and Scambler that:

... hearing Mishler’s voice of the lifeworld need and should not lead to the eclipse of the voice of medicine. Lifeworld decolonization requires only that the limits of expert systems are acknowledged and that doctors remain collectively and individually accountable to the populations they serve (2005a:18).

Patients do not always wish to be involved in joint decision-making about therapeutic options: they trust the HCPs’ expertise in this (Bissell *et al.* 2003). What they do want is the practitioner to hear and understand the life situation in which they live, the structural constraints and enablements within which they would exercise their agency in their medicine-taking decisions. They also expect that the HCP will be honest with them: put simply concordance promotes ‘respect for the patient’s agenda’ (Bissell *et al.* 2003:498).

As the role of the GP [HCP] changes with the rise of chronic illness in an ageing population GPs [HCPs] may have to change their notions of success from purely technical considerations to include their patients feeling understood, listened to and treated like whole and unique human beings. However, there will be a need for structural reforms to provide a suitable framework within which GPs [HCPs] can be supported to offer this type of care (Barry, Stevenson, Britten, Barber & Bradley 2001:504).

5.1.5 *What does concordance ‘look’ like?*

Concordance as an approach to HCP/patient relationships, originates from concerns regarding medicine-taking decisions (by both HCPs and patients). It therefore lends itself to the pharmacist/patient relationship (Chewning & Weiderholt 2003) and particularly to pharmacists’ support of people living with chronic illness (FIP 2003). The three figures below offer diagrammatic representations of concordance. The first two represent the understandings proposed by the Medicines Partnership (FIP Figure 5-2) and the International Pharmaceutical Federation (Figure 5-3) respectively. The third figure (5-4) Presents my proposed understanding based on modifications to the FIP model:

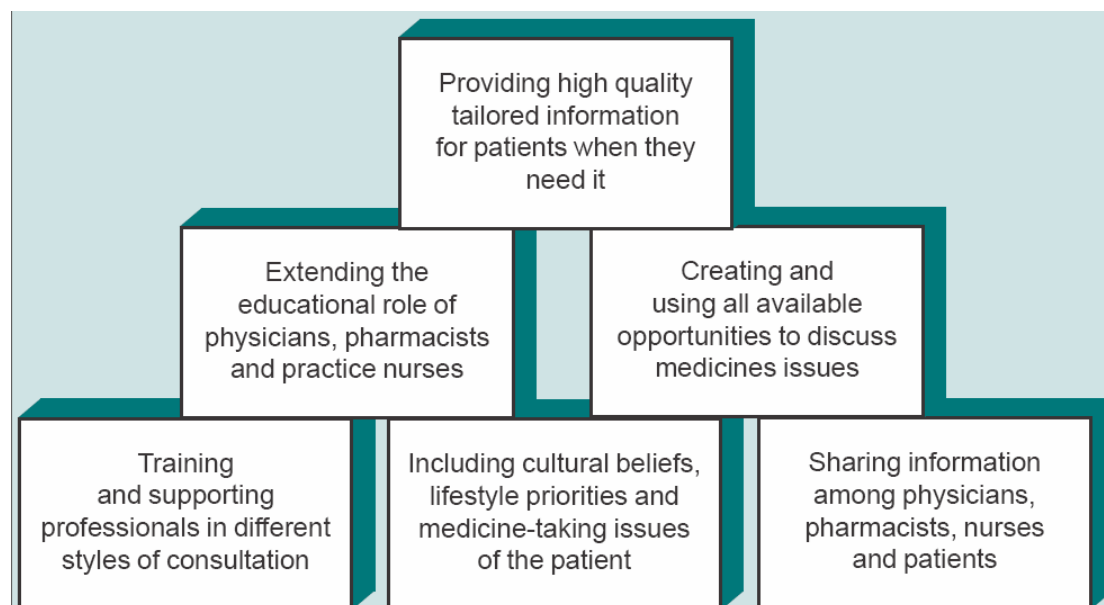


Figure 5-2: Building Blocks of Concordance (FIP 2003:513)

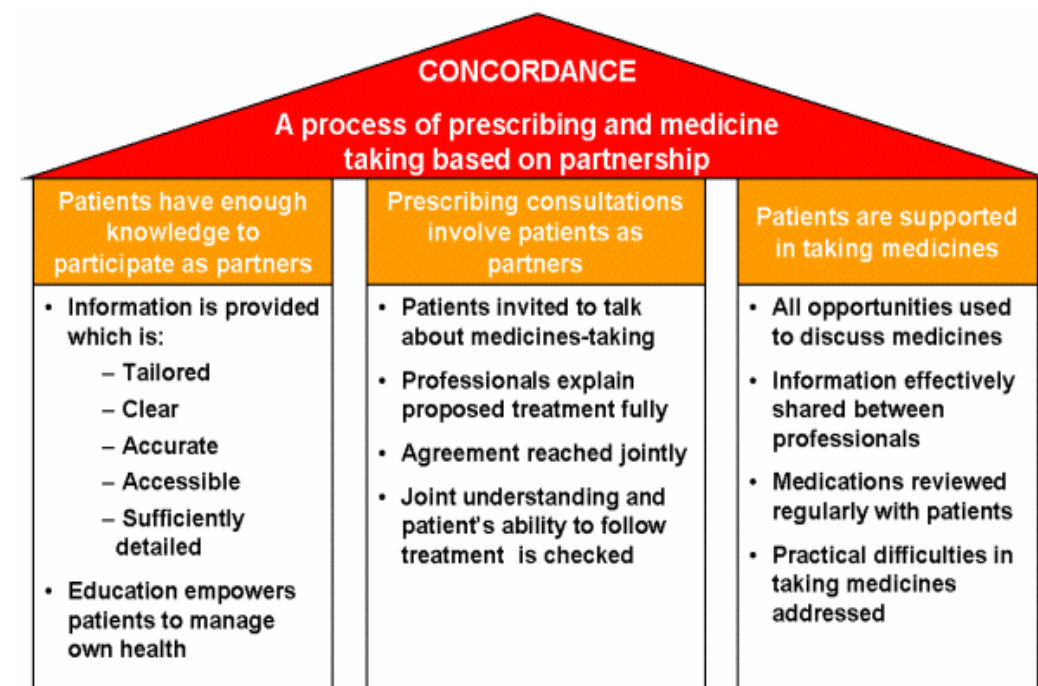


Figure 5-3: Medicines Partnership (Fish 2004)

While the models display obvious similarities, the FIP model appears to avoid the paternalism evident in the MP model, and offers a more sophisticated awareness of the complexity of medicine-taking decisions. The MP model, however, makes the goal of supporting the patient in her/his decisions slightly clearer.

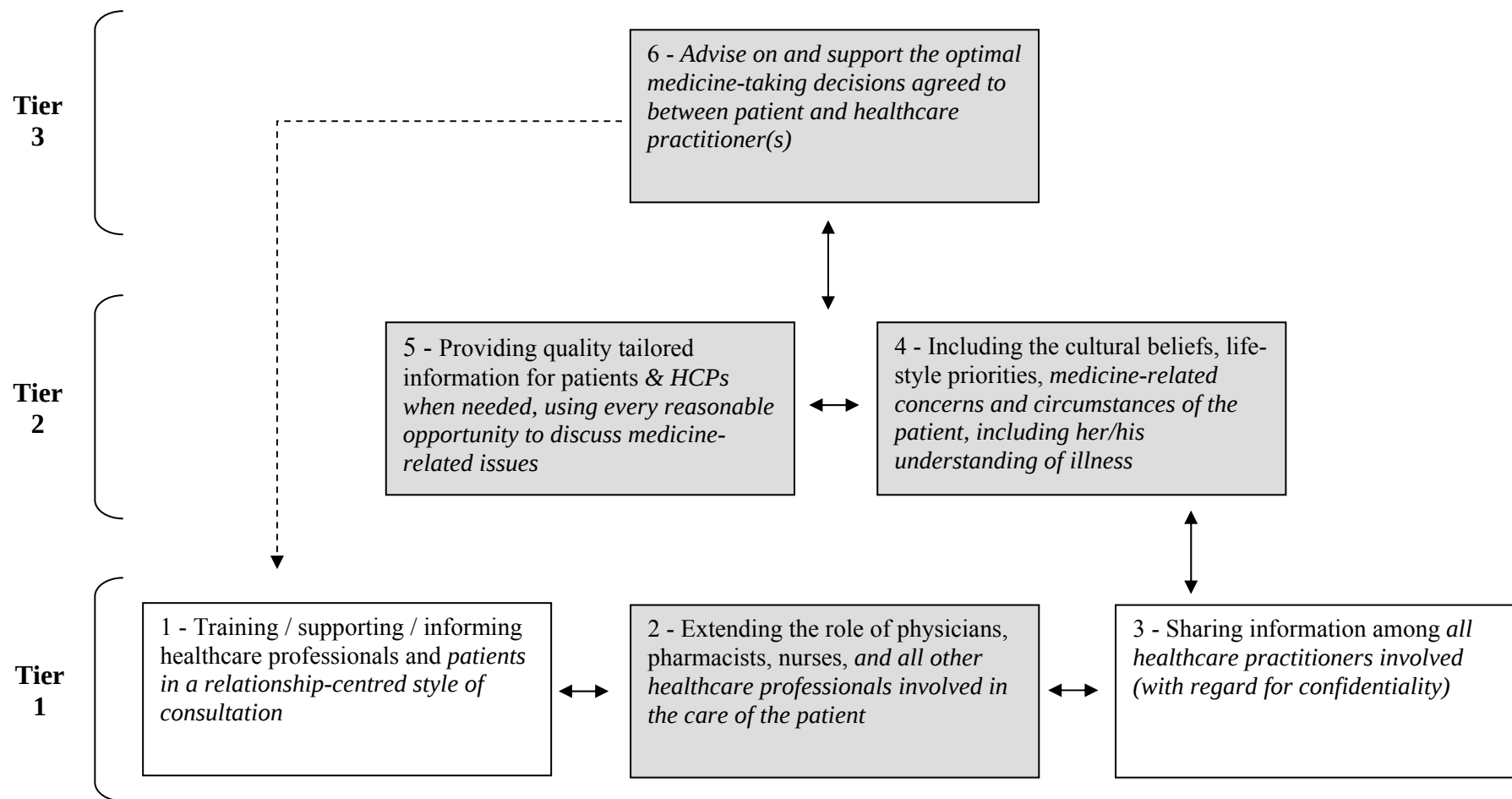


Figure 5-4: Proposed model of concordance for pharmacists (numbers inserted for purposes of discussion)

Figure 5-4 above represents my adaptation of the FIP model (Figure 5-2). This adaptation is in line with the understanding of professionalism proposed by Evetts (2003 and discussed in detail below - 6.2.2), and takes into consideration the caveats regarding concordance noted above (5.1.4). The diagram is divided into three tiers. The tiers are not impermeable, but serve to indicate the foundational aspects in order for the process to move toward its goal. Rather than seeking to achieve patient behaviour that aligns with HCPs' instructions, the goal of concordance is an agreed approach to an optimal therapeutic regimen in which the active roles of all participants are acknowledged. This adaptation is intended to make clearer both the goal of the process and the active role of the patient. Shaded boxes represent boxes that have been moved from the positions they held in the FIP diagram, while italicised text indicates my revisions or additions.

In the first tier of Figure 5-4, box (1) remains in the same position as the FIP model (Figure 5-2). The training of HCPs in a new approach to considering therapeutic decision-making, is fundamental to any attempt to shift the discourse of HCPs from compliance to a genuine therapeutic alliance, focused on optimal use of medications, rather than 'rational' use of medication. One addition has been made, however, and that is to recognise that patients will be unaccustomed to this approach to therapeutic decision-making, and this needs to be considered in implementing concordance.

Box (2) introduces a change from the FIP model, with the extension of the HCP's roles made more fundamental. The physicians occupy the central role in compliance models (Trostle 1985; Playle & Keeley 1998), but in many cases patients have greater contact with other HCPs (for example clinic nurses and pharmacists) than with their physicians. In a relationship-centred model of healthcare practice (2.2.2.3 above), the roles of the HCPs must be extended to meet the needs of the patient in their context. They must not expect the patient to comply with an ideologically driven hierarchy. Box (3) – its position unchanged from the FIP model – supports this extension of roles. Pharmacists or clinic staff who have greater contact with patients, should be in the position to share (with the patient's permission), relevant information with other HCPs involved in the support of the patient. This may involve creating the possibility for the patient her-/himself to inform another HCP of information that is important for their support.

On the second tier of the model (Figure 5-4), box (4) serves to highlight what information is appropriate, and for ‘tailoring’ the information for the patient’s needs. For example, if the pharmacist knows that the patient is an avid competition cyclist (a lifestyle priority), but the patient is on cyclosporine⁴, then it would be unlikely that telling the patient to stay out of the sun to reduce the likelihood of skin cancer, is going to be acceptable. Rather, agreeable compromises will be more effective: an informed patient may wear longer-sleeved cycling gear, use sun-block, and be alert for signs of skin cancer. Thus an optimal decision is reached, which is not based on the assumption of passive obedience, and so the issue of ‘covert disobedience’ (non-compliance) does not arise. Box (5) underlines the professional role of the pharmacist as the expert on medicines (6.2 below), and makes clear the relationship-centred perspective of concordance. The pharmacist must use her/his expertise to identify times when the patient (and other HCPs) may need information, but must also be ready to respond openly to requests from either the patient or HCPs. Such a response must include honest and appropriate discussion of DRPs / ADRs with the patient or caregivers.

Box (6) provides the focus of the pharmacist’s role: the provision of advice and other support (including timeous supply of medication and related resources such as measurement devices, droppers and so on), in a manner which supports the agreed *medication practice* of the patient: ‘Medication practice offers a patient-centered perspective of how people manage their medications, focusing on the meaning and use of medications’ (Conrad 1998:31) in the light of their understanding of their condition.

If the focus of the concordance model is the support of optimal medicine-taking decisions, then the model cannot be regarded as a simple hierarchy. Each ‘position’ must inform the one(s) prior to and after it. The positioning of the physician as superior in the model would be detrimental to the care of the patient; just as the assertion that the patient’s knowing is superior to the physician’s would be inappropriate (Stevenson and Scambler 2005a). In the supercomplex age in which health must now be understood, it is neither helpful, nor possible, for a single individual (albeit as a member of a profession) to control the knowledge and decisions relating to the care of chronic illness. In any event, such ‘control’ as may exist, ends when the patient leaves the consultation, pharmacy or hospital and

⁴ Cyclosporine is an immunosuppressant occasionally used in the treatment of autoimmune conditions and in post-graft transplant recipients. One of its many side-effects is a marked increase in susceptibility to skin cancers.

engages in their medicine practice in the context of the open-system of their lifeworld (Pound *et al.* 2005).

Concordance creates the opportunity for recognition of the patient's agency in an engagement between a patient and HCPs regarding medicine-taking. In part, this facilitates the HCPs' access to the patient's understanding of the 'meaning of medications' (Conrad 1985). Pound *et al.* (2005) review the range of ways in which people, especially those living with chronic illness, engage in medicine practices. Fundamental to these practices is an underlying mistrust of medication:

The significance of the lay evaluation of medicines lies not simply in the fact that it occurs, but in the reasons why it occurs. The urge to evaluate suggests widespread caution about taking medicines as well as distrust in the information given about medicines. It may also reflect an intuitive understanding that population set doses may not be appropriate for individuals (Pound *et al.* 2005:149).

This mistrust, as they go on to argue, is not unfounded. If the HCP is aware of the mistrust, and supports the patient in the monitoring of his 'lay evaluation' of his medication, then the HCP is likely to be better informed regarding the way medication affects the patient. Moreover, the level of trust vital to a professional relationship is more likely to develop and be maintained. 'Support' does not mean uncritical agreement – the HCP is professionally obliged to present her opinion, but if that opinion is open to the patient's (often) legitimate fears, then an optimal medicine practice appears more likely (Conrad 1985; Donovan & Blake 1992; Stevenson *et al.* 2002; Pound *et al.* 2005).

With respect to medicine usage, the pharmacist's 'knowing' becomes a vital element of the support needed by the patient. This means that, for example, the pharmacist must be aware of repeat scripts that are required, note the frequency of these, and be aware of possible health-related problems that may be signalled by late collection of scripts. The pharmacist must also be aware of alternative medication options, of potential contra-indications and side-effects of which the patient (and perhaps the prescriber) is not aware. The pharmacist must, in other words, practice *pharmaceutical care* (6.2.3 below). The following chapter thus provides a consideration of pharmacy as a profession, and the importance of pharmaceutical care as a philosophy of practice.

Chapter 6: Pharmacy, Professionalism and Pharmaceutical Care

The shifting responsibilities for health maintenance, as illustrated by the deregulation of medicines, present the community pharmacy service with opportunities to claim a more prominent role in health care. Our analysis of the strategies which underpin the everyday act of buying medicines suggests that consumerism represents a significant challenge to the accomplishment of medicines surveillance and professional work in the community pharmacy (Hibbert, Bissell & Ward 2002:62).

The grocers were allowed to sell drugs and spices and became known as druggists (Traulsen & Bissell 2004: 110).

6.1 Introduction

The previous two chapters presented an overview of debates regarding disease, illness and sickness, and the related concerns surrounding medicine-taking decisions. In Chapter 4 I argued that any understanding of healthcare based on the biomedical disease discourse is limited in its relevance to the increasing complexity of healthcare in the 21st century. I argued that a holistic, contextualised approach, which recognised individual patient's *illness* discourse and society's *sickness* discourse, is essential in supporting therapeutic decisions. In Chapter 5, this argument was developed further through a brief overview of the debate around compliance and adherence in the extensive literature on medicine-taking decisions and behaviour. I argued that the biomedical, disease-focussed compliance discourse is inadequate as a way of understanding patient medication practices, especially in chronic illness. I then supported the proposed use of concordance as a holistic way of approaching the therapeutic decision-making process involving the use of medications. I concluded by suggesting that pharmacists are well placed to facilitate the replacement of the one-dimensional compliance discourse as a way of describing and discussing patient medicines practice, with the discourse of concordance. I further suggested that through a redefined understanding of itself as a profession, centred on the philosophy of practice of pharmaceutical care, pharmacists may best support optimal medicine practices among patients living with chronic illness. It is with an understanding of both pharmacy as a profession and pharmaceutical care as its practice, that I am concerned in this chapter.

Congruent with the social realist theoretical perspective outlined in Chapter 2 (2.3.2 – 2.3.5), this chapter will argue for an understanding of pharmacy which recognizes the *reflexive practice of pharmacists* and the *context in which they practice*, as well as the

enablements and constraints of social structure that reflect the shifts in understanding of health (including the rise of the 'consumer') coupled with the professional dominance of medicine. Part of the context is geo-historical (pharmacy practice in South Africa at the beginning of the 21st century), and so the particular debate over the (social) role of pharmacy in relation to medicine will frame the discussion of pharmacy as a profession. At the same time the debate over the identity of pharmacy as a profession (and therefore of the social identity of the individual pharmacist), has been on-going since at least the last century and has an international context which must be considered. While I recognise that pharmacy as a profession/occupation extends beyond community, hospital, or clinical pharmacy, and includes industrial, research and academic pharmacists, the central focus of this study is on the preparation of pharmacy students to support people living with chronic illness in their medicine-taking decisions. In this chapter I will foreground *pharmacy practice* understood as 'those activities of pharmacists that most closely and directly impact on or interact with the final consumer of medicines, be they patients or users' (Wingfield, Bissell & Anderson 2004:2384).

6.1.1 Pharmacy education – a preface to the profession

As an educational curriculum is rooted in a discipline's understanding of itself, the growing dissatisfaction with pharmacy education (Gray & Bodley Smit 1998; Das & Das 2001; Robinson 2003; Traulsen & Bissell 2004) will be difficult to address without a critique of the way pharmacy understands itself as a profession, and of the ways in which pharmacy practice is understood. I will use a socio-historical overview of the development of pharmacy and its contested self-definition as a profession, as a way of framing a sociological understanding of pharmacy. Within this account the literature relating to *pharmacy practice* (FIP 2001) is dominated by *pharmaceutical care*. Pharmaceutical care was proposed as a way forward for pharmacy practice in the face of what has increasingly been seen as its fragmentation and 'deprofessionalization' (Denizin & Mettlin 1968; Hepler 1987). Fundamental to pharmaceutical care is patient-centeredness. In its strongest formulation, pharmaceutical care is based on a covenantal relationship between pharmacist and patient (Hepler 2000). This 'strong' formulation focussed on seeking optimal medicine-taking behaviour through multi-disciplinary teamwork and person-centred practice (a biopsychosocial approach), as opposed to compartmentalised product- (drug-) centred practice (a biomedical model).

Both national and international pharmaceutical professional bodies argue for pharmaceutical care as a defining philosophy of practice (Posey 1997; FIP 1998; Lubbe,

Serfontein & Lamprecht 2003). A survey conducted by Lubbe, Serfontein, Futter, Steyn, & Serfontein (2000), however, revealed apparent resistance by practicing South African pharmacists to the approach or 'philosophy' of pharmaceutical care. Central to the reasons given by pharmacists participating in this survey for this lack of take-up, was lack of remuneration linked to the practice required. As Gilbert notes, the issue of remuneration for pharmacists has long been, and continues to be, at the heart of the debate about pharmacy in South Africa (Gilbert 1998; 2004a). Despite concerns such as these the urgent calls for pharmacy practice to be guided by the principles of pharmaceutical care persist (Hepler 2000; FIP 2001; Lubbe, Serfontein & Lamprecht 2003; Anderson 2005; Zellmer 2005), and continue to be linked to the need for pharmacy to have sufficient theoretical and moral ground to claim its place in society as a profession. The current political, social, and professional challenges to pharmacy demand a critique of current understandings of pharmacy and pharmaceutical care in South Africa (Gilbert 2004a & b). In the light of these challenges, I argue that directions for change for South African pharmacy practice may be suggested by a re-consideration of the understanding of pharmacy as a profession.

Lubbe *et al.* (2001) and Gray and Bodley Smit (1998) argue that inadequacies in South African pharmacy education lie behind the reluctant take-up of, and apparent lack of understanding of the urgency for, pharmaceutical care. This assertion is supported by a substantial amount of the international literature calling for changes in pharmacy practice that must necessarily be preceded and supported by changes in the approach to pharmacy education (Hepler 1987; Hepler & Strand 1990; Gray & Bodley Smit 1998; Das & Das 2001; Robinson 2003; Traulsen and Bissell 2004). Traulsen and Bissell (2004) reflect the concerns which form the background to this study:

Traditionally, pharmacy has been based in the natural sciences, with an emphasis on technical skills. Within the past 60 years, it has lost three of its four mainstays (drug procurement, storage, and compounding) to industry. These three tasks neatly fit into what is referred to as the technical paradigm (emphasising pharmaceuticals and their preparation). What is left is the task of dispensing, a task which in its narrowest sense can be approached as marketing and sales. *In the broadest sense, the pharmacist is perceived as an active member of the health care team, for example, in the case of clinical pharmacy and pharmaceutical care with responsibility for inter-professional as well as patient consultation. This role falls in areas of expertise that do not fit into the technical paradigm but belong to an entirely different paradigm: one that emphasises a disease- and patient-oriented approach to pharmaceutical decision-making.* Research shows that when legislation makes new demands on the workplace, pharmacists can find that the skills required of them in their daily work are not always those they were trained to do (Traulsen & Bissell 2004: 111 *Italics added*).

Education for pharmacy practice appears to be in need of review. In part this may be because pharmacy education has been insufficiently theorised (Robinson 2003), but even deeper than that, pharmacy as a profession is itself under-theorised (Bissell & Traulsen 2004). Frequent reference is made in the pharmaceutical care literature to ‘professional’ behaviour, while the meaning of ‘professional’ remains undefined or, at best, vaguely aligned to medical definitions. Since pharmacy is silent on its understanding of ‘professional’, it has allowed medicine and others to increasingly ‘define’ pharmacy out of the professions (Gilbert 2001; Traulsen & Bissell 2004; Anderson 2005).

6.1.2 Pharmacy in South Africa

Gilbert paints a bleak picture of pharmacy in post-democracy South Africa as a profession positioned (geographically and socially) in the wrong place to respond to the urgent healthcare needs of a society in transition (Gilbert 2004a). She argues that while pharmacists in South Africa want to claim an active role as healthcare professionals, the profession (and the majority of pharmacists) remain trapped in the traditional role of dispenser subject to medicine, a role for which, ‘consistent with the literature, they are over-trained and underutilised, resulting in despondency, frustration and general dissatisfaction with being a community pharmacist’ (Gilbert 2004a:305). However, she goes on to argue that changes in the wider social structure of healthcare, while they constitute a climate of uncertainty, also offer an opportunity for pharmacy to cross traditional boundaries, and work with other professionals to meet the demands of a society influenced by new understandings of health, including what Gilbert terms ‘CAM healers’ (Complementary and Alternative Medicine) and nurses (Gilbert 2004a: Abstract; 314; 2004b). She concludes that:

...although traditionally clarity exists with regard to the boundaries of professional task domains, the growing-emphasis on PHC [Primary Health Care] and team work has tended to obfuscate them and imply ‘vacancies’ in jurisdiction. This has been further fuelled by the growth of CAM and the health movements. Universally, but in South Africa in particular, pharmacy as a profession in transition in search of greater responsibilities recognizes this as an opportunity to redefine its role (Gilbert 2004:315).

The vulnerability of pharmacy limited to dispensing, noted by Traulsen and Bissell (2004), is well illustrated in the impact of recent amendments to legislation in South Africa, especially with respect to prescribing doctors, and, potentially to prescribing nurses (SA Government 1965; 1974; 2004; Thom 2004). The situation in South Africa (indeed in many African countries) is exacerbated by the relatively low ratio of 23 pharmacists per

100 000 of the population (Anderson 2002:402)¹. Cultural and socio-economic developmental factors further impact on South African pharmacy in that, as with other developing countries, ‘the contribution that pharmacists can make is largely determined by the availability of pharmaceuticals. Where these are not available, for whatever reason, the need for pharmacists is reduced.... [In addition many people]... make substantial use of traditional remedies and have large numbers of traditional healers involved with the making and supplying of medicines’ (Anderson 2002:401). While new legislation in South Africa affects the whole spectrum of healthcare, coupled with the concomitant emergence of the supermarket chain pharmacy and the licensing of dispensing doctors, it threatens the independent retail pharmacist with closure in a way very similar to the earlier experience in the US and, to a lesser extent, the UK (Birenbaum 1982; Holloway, Jewson & Mason 1986; Traulsen & Bissell 2004; Thom 2004).

Pharmacy in South Africa defines itself as:

a dynamic, information-driven, patient-oriented profession, [which] through its infrastructure, competence and skills, is committed to fulfil [*sic*] the healthcare needs of South Africa and its people by being the:

- a) Custodian of medicine;
- b) Formulator, manufacturer, distributor and controller of safe, effective and quality medicine;
- c) Advisor on the safe, rational and appropriate use of medicine;
- d) Provider of accessible, essential clinical services, including screening and referral services;
- e) Accessible provider of health care information;
- f) Provider of pharmaceutical care by taking responsibility for the therapeutic outcome of a therapy and by being actively involved in the design, implementation and monitoring of an effective pharmaceutical service;
- g) Profession committed to co-operation with members of the health care team in the interests of the patient; and
- h) Profession committed to cost-effective pharmaceutical services (South African Pharmacy Council - SAPC 2004:1).

This self-understanding (at least in official form) by South African pharmacists, is revealing. Clearly there is no sense that pharmacy has ‘lost’ manufacturing and compounding to industry (*vide* Traulsen & Bissell), as the pharmacist is still seen as responsible for such practice. Not surprisingly medicines are regarded as central to the role of the pharmacist, but items (c) – (f) significantly expand on the simple ‘dispensing²’ of a medicine. Although there is some ambiguity in the phrasing of (f) with regard to what is meant by ‘responsibility’, pharmaceutical care is clearly regarded as significant. Some

¹ Figures for 1999 – 2000. Anderson cautions that figures for the developing world are not accurate, but approximate the position (2002:401).

² See Glossary.

clarity as to what is meant by ‘taking responsibility for the therapeutic outcomes’, is available later in the document (SAPC 2004:2), where pharmaceutical care is described as including among other things:

- ‘*taking responsibility for the patient’s medicine-related needs and being accountable*³ for meeting these needs’ (italics added);
- evaluation ‘of a patient’s medicine-related needs by determining the indication, safety and effectiveness of therapy’; and,
- ‘determining patient compliance with the therapy and follow-up to ensure that the patient’s medicine-related needs are met’.

Each of these reflect power relationships *vis-a-vis* both patients (‘compliance’) and prescribers (evaluation of medicine-related needs). This is underscored in the statement that the *pharmacist* ‘takes responsibility for’ the patient’s medicine-related needs (including compliance monitoring). Taken together these reflect not only a clear assumption of authority over the patient (at least with respect to medicine use), but also a demarcation of professional boundary between medical practitioner and pharmacist. This last matter is significant in the context of the current (2004 – 2005) debate around the consequences of the recent legislation in South Africa relating to drug pricing, charges levied by pharmacists and licensing of other healthcare practitioners as dispensers (Thom 2004), as well as in the ongoing struggle for professional power between pharmacy and medical practitioners in South Africa (Gilbert 1998; 2001; 2004a).

6.2 Pharmacy, (De- / Re-) Professionalization and Pharmaceutical Care

In too many practice settings, the pulse of pharmacist professionalism is weak or nonexistent. Resuscitation is urgently needed. Unless that revival occurs, there is no assurance that pharmacists will continue to be required in the prescription dispensing process (Zellmer 2005:261).

The history of pharmacy is not simply one of developing technology, but substantially of a struggle for recognition as a profession, first in separation from religious control (Turner 1987) and thereafter in a frequently bitter struggle with medicine (Birenbaum 1982; Holloway, Jewson and Mason 1986; Hepler 1987; Gilbert 2001; Traulsen & Bissell 2004). Caught between a business-for-profit and an altruistic profession of care; dominated by medicine; fragmented across retail / community / manufacturing / administrative and hospital pharmacy; almost rendered peripheral by the economics of the pharmaceutical industry’s collusion with medicine and commerce; pharmacy has been described in

³ Who holds the pharmacist accountable is not made explicit, reflecting the ‘professional’ understanding of only professionals being able to hold professionals accountable (see Geisler 1994 & 6.2.2 below).

sociological literature as an ‘incomplete, marginal and limited’ profession (Turner 1987:145; Edmunds & Calnan 2001:943).

Until recently sociology has paid scant attention to pharmacy, largely because pharmacy lacked autonomy and power as a social institution (Turner 1987; Ryan, Bissell & Traulsen 2004). With growing focus on the professions by society in general and by the state in particular, pharmacy is increasingly coming under the spotlight (Traulsen & Bissell 2004; Ryan, Traulsen & Bissell 2004). This has been acutely so in South Africa in 2004 with the impact of the Medicines and Related Substances Amendment Act (S.A Government 2002) and related legislation (Thom 2004), and with challenges to the wider expression of pharmacy in its attenuated guise as the pharmaceutical industry, especially with regard to HIV/AIDS treatment. Although the underlying socio-philosophical concerns are arguably generally applicable to pharmacy, this study is primarily concerned with education for pharmacy practice, and therefore with retail, community service, and hospital pharmacy practice.

6.2.1 Pharmacy

The history of the development of pharmacy has been well covered elsewhere (Hepler 1987; Lubbe 2000; Traulsen & Bissell 2004). What follows provides a brief overview of that history (Table 6-i), and some reflection on the impact of aspects of the history on pharmacy practice.

Events within pharmacy		Events impinging on pharmacy
Greek physician Claudius Galenus	3 rd C	
Purveyors of spices and drugs under the auspices of the Society of Grocers in Britain	13 th C	Holy Roman Empire, pharmacy first separated from medicine
Society of Apothecaries formed in Britain (responsible for the manufacture, compounding and dispensing of medications that were largely drawn from plants and where required, mixed with honey, milk, beer or wine)	1671	
‘Chemist apothecaries’ emerge	18 th C	Beginning of chemistry’s impact on pharmacy
First Pharmacy Society formed in Britain	1841	
Admission examinations established (‘pharmaceutical chemists’)	1852	
Apothecary complaints about being reduced to mere dispensers / shop-keepers	1858	Beginnings of industrialization of pharmacy with Eli Lilly and Upjohn during late C. Manufacturing (including much compounding) begins to be taken over from pharmacists
Separation into ‘chemists’ (‘Major exam’) & ‘druggists’ (‘Minor exam’)	1868	
	1940’s	US Government refuses to give pharmacists status as ‘professionals’ for military service
Hospital pharmacists established in the US	1950’s	
Community pharmacists restricted to dispensing		
Call for (re)professionalization around ‘drug use control’ (Brodie 1967)	1960’s	
Beginnings of clinical pharmacy		

Term 'pharmaceutical care' first used in 1975 as description of professional role of pharmacist (Mikeal in Brodie 1967) Hepler calls for clinical pharmacy model based on 'covenantal relationship' between pharmacist, patient and prescriber Hepler and Strand publish first comprehensive model of pharmaceutical care as a philosophy of practice Interim Pharmacy Council of South Africa explicitly asserts pharmaceutical care as philosophy professional practice	1970's	HIV/ AIDS Pandemic emerges
	1987	
	1990	
	1997	
	2002	Legislation in South Africa appears to restrict medical practitioners' dispensing rights, but leaves a 'back door' of licensing at the discretion of state authorities
	2004	Legislation in South Africa • limits pharmaceutical manufacturers' profits; • restricts opening of retail pharmacy practices while permitting chain stores to establish pharmacies, and expand (with registration) the range of healthcare professionals with dispensing rights; • restricts profits on medication sold by pharmacies.
	2005	First pharmacies begin to close in SA, in part as a result of impact of legislation

Table 6-i: Overview of the development of pharmacy (Brodie 1967; Hepler 1987; Turner 1987; Jackson 1999; Lubbe 2000; Gilbert 2001; SA Government 2002; Thom 2004; Traulsen & Bissell 2004)

While the apothecary movement in Britain won social acceptance through a focus on what was primarily the emerging middle class, in the US medical professional dominance was already so established that pharmacy was relegated to 'technical support roles' almost from its inception (Kronus 1975 in Birenbaum 1982:871). The slightly later separation of pharmacy from medicine in the United States was as much a limit on 'conflict of interest' in medicine between the roles of prescriber and dispenser, and to prevent doctors profiting on both consultation and medication, as it was to put in place a safety check on medication (Gilbert 2001:98).

This late 19th and early 20th century period can be characterised as the 'Empirical era' of pharmacy (Hepler 1987). Essentially pharmacy was still a science of pharmacognosy (treatments from nature) and followed time-honoured Galencial methods based on Roman physician Claudius Galenus' (AD 130 – 199) use of mechanical methods to grind products to grain or powder form (Hepler 1987; Marks, Murray, Evans & Willig 2000; Collins Dictionary). Increasingly the manufacture of drugs separated from dispensing and allied with science and industry, while pharmacy practice (dispensing and direct contact with patients) became subservient to medicine. These divisions, which accompanied the developing alliance with science, assumed a greater portent when the commercial interests

of manufacture began to expand during the mid-century (Gilbert 2001). In the process of allying itself to science during the 19th and early 20th centuries, pharmacy found itself increasingly subject to the social and political (i.e. professional) dominance of medicine. When pharmacy lost what control it had over manufacturing, procurement, storage and compounding of drugs, all that was left was dispensing (Gilbert 2001; Traulsen & Bissell 2004).

6.2.2 (De- / Re-) Professionalization

It is impossible to consider a sociological perspective on the healthcare professions without examining the understanding of ‘professional’. While Dingwell & Wilson (1995 in Traulsen & Bissell 2004:111) argue that the debate is ‘sterile’, and more would be achieved examining what pharmacists do – I argue that pharmacy has not examined its own self-definition of ‘professional’. Despite this, pharmacy continues to define itself as a profession. However, because this directly impacts on the educational practices of pharmacy Faculties (Hepler 1987; Futter 1997; 2002), it is important to be clear as to the understanding or ‘professional’ that is in use.

The emergence of sociology as a discipline toward the end of the 19th century closely corresponded with the tenuous emergence of pharmacy as a distinct ‘profession’. Turner (1987), Nettleton (1995), Annandale (1998), Evetts (2003), and Traulsen and Bissel (2004) trace the changes in sociological conceptualizations of the professions during the 20th century, noting that the medical profession has occupied centre stage in socio-philosophical understanding and debate around the meaning of ‘profession’ itself. Regrettably ‘the sociology of the professions is in “an intellectual shambles”....’ (Freidson 1994, in Annandale 1998:230). This characteristic is to a large extent related to the discourse of paradigms adopted by sociology. This ‘lack of theoretical continuity’ (Turner 1987:133) within sociology itself, and with regard to the understanding of what is meant by ‘profession’, coupled with changes in society and within pharmacy itself, makes it difficult to map the status of pharmacy as a profession since the late 19th century. That said, Geisler (1994), writing from the perspective of seeking to understand the construction of academic literacy as bound up with the concepts of expertise and professionalization, provides a usefully coherent account for and of the rise of what she terms ‘occupational professions’, among which she includes pharmacy.

Focusing primarily on the United States, Geisler (1994) traces two different strands in the development of the professions. The first strand relates to the long established ‘possessors’

of arcane knowledge – religion, law and medicine, tied as they were to upper class membership. The second strand, those she terms the ‘modern’ or ‘occupational professions’, consists of those professions which established themselves in the late 19th century. These begin with dentistry in 1840, and including a range from accounting to veterinary practice. Included in these occupational professions are nursing (1896) and pharmacy (1854).

Geisler argues that this wave of professionalization emerged from industrialization. Professionalism was only possible because of the increase in wealth and resources made available by industrialization. On the one hand, industrialization provided the wealth which made possible the education and training required for these new professions. This permitted people to leave the labour force long enough to undergo the increasingly long periods of education required by the professions. On the other hand, the continued growth of the industrialized economy required a larger pool of well-resourced people with disposable incomes, to fuel the continued growth of an industrialized economy. Because the occupational professions demanded greater compensation for services than the groupings they replaced (the pharmacist in the case of the druggist; the gynaecologist in the case of the midwife; the engineer in the case of the builder; and so on), they fed back into the economy the disposable resources needed to maintain momentum.

The expansion of professions was not only a product of burgeoning market economies, but ironically was also a reaction to the socio-economic consequences of industrialization. Professions formed a bulwark against what was viewed as the crass commercialization of society and an over-emphasis on individual gain at the expense of service (Evetts 2003). Professions thus acted as ‘special market shelters’ for people whose work, while remunerated, was driven by service to society and not mere production (Geisler 1994:70). Professions, however, had to provide evidence of justification for their special protection, and Geisler argues that this evidence lay in the development of an ‘academic guarantee of expertise’ (1994:72). This justification became the driver for professions to be defined as custodians of expertise (‘knowledge that was different from and subsequent to liberal studies [and the common knowledge of the layperson]’ – Geisler 1994:74).

Crucial to the current debate about pharmacy as a profession, and an issue to which I shall return later, Geisler argues (quoting Haskell 1977), that the motivating social force behind this sudden demand for the expansion of the professions was:

a reaction to the widespread failure of the classic professions to provide satisfactory advice to a society in the grip of increasing complexity. In essence, the local lawyer, doctor and priest could no longer provide citizens with enough control of their daily existence to maintain traditional authority, and new professions stepped in to fill the gap (Geisler 1994:70 *Italics added*).

The complexity of this period of professionalization was rooted in dramatically reduced communication time allowing for the rapid spread of information. Coupled with equally dramatic urbanisation, exacerbated by population growth, and complicated by increasing concentrations of diversification of cultures of an order not before experienced, it became clear that old ways of thinking could not keep pace with the changes (Haskell 1977 in Geisler 1994).

Geisler's account helps explain why the traditional understanding of profession, originating from the functionalist orientation linked to Durkheim, found such ready acceptance. In functionalism, professions are primary among those institutions *committed to sustaining societal values* (Traulsen and Bissell 2004); *marked by altruism*, with a 'disinterested commitment to community welfare' (Turner 1987:131); and *rooted in possession of a body of specialized knowledge* (Nettleton 1995). The functionalist perspective was subsequently modified by Weber's linking of profession to calling, with strong links to the religious concept of a calling to service without concern for reward (Turner 1987). Additional layers of understanding developed, seeing the professions as marked by objectivism and removed from the influences of baser 'sectional interests' (Turner 1987:131). Related to this was the essential characteristic of the profession, trust. Society had to be able to trust the professional which in turn has meant that professional status depends on society granting that trust (Evetts 2003). These conceptions of profession clearly bear the elements of a positivist epistemology, in which knowledge exists outside the learner as a 'body of knowledge' to be acquired, and is characterised by objectivity. The possession of, and control over, specialized knowledge were fundamental to early understanding of professions and remain so today (Geisler 1994; Nettleton 1995; Traulsen & Bissell 2004; Anderson 2005). Geisler (1994:72) argues that the possession of specialized knowledge ('the cognitive bedrock') was the basis for the characteristics of a profession in the 20th century, namely:

- *Autonomy* – expert knowledge was beyond the uninitiated and so only those with the knowledge (those in the profession) could control the profession – entry, peer review and defining their tasks;
- *Status* – expertise required time to develop and required certain often indefinable characteristics. Professionals thus deserved higher remuneration because of both

the sacrifice involved in acquiring this knowledge, and so that society could persuade them to make that costly knowledge available to others through service;

- *High standards of commitment to service and control of their behaviour* precisely because their knowledge placed them above evaluation by outsiders.

An important consequence of the centrality of ‘cognitive expertise’ was the requirement for a ‘credentialing system’ (Geisler 1994:72, 73) – and here the influence of the profession over the curriculum of university (an ideological as well as content influence) became evident. Professions and education became inextricably linked, and the way the profession understood itself directly impacted on what must be taught, and who may teach, in the credentializing institutions. Education then had to keep pace with the demands of the profession, a problem with which pharmacy education has continually struggled (Hepler 1987; Traulsen & Bissell 2004), and a problem certainly exacerbated by pharmacy’s apparent inability to secure independent professional status.

In 1970 Freidson argued that professionalism is marked by a desire to control (*‘professional dominance’*) (Nettleton 1995:197 *Italics original*). This was especially evident in the medical profession, which could thus ‘subordinate adjacent and related occupations, keeping them permanently in the status of quasi-professions or paramedical groups’ (Turner 1987:132). An inherent element of the functionalist understanding of ‘profession’, with its emphasis on cognitive expertise, is the power to control not just other occupations, but even – and indeed especially, in the case of medicine – the needs of the market’s consumer (Nettleton 1995). This power is based on:

social distance...and their relative access to socio-economic resources....if doctors have relatively more intuitive and non-routinized [*sic*] intelligence than codified and openly accessible knowledge, then there will be greater social distance....Consumers of medicine have little say about their health and illness because it is presumed that they will have limited understanding and knowledge about medical science (Nettleton 1995:197 – 198).

As noted earlier, central to this understanding of profession is the presumption of *autonomy of occupational control* (i.e. that only those within the profession have sufficient knowledge to control the profession – Nettleton 1995; Annandale 1998). This opens a profession to abuse within, and mistrust from those outside (Annandale 1998). Marxist critique of the professions – especially the medical profession – proceeds from this mistrust, arguing that all professions contribute to the control of society by the capitalist class (Turner 1987; Nettleton 1995; Annandale 1998).

A further development of the Marxist approach became known as ‘proletarianization theory’ (Annandale 1998:225; Traulsen & Bissell 2004:109). Proponents of the ‘proletarianization theory’ argued that professionals would lose their power and become simple wage earners employed (in the case of medicine) by the state or large corporates, such as managed health care organisations. This theory has largely been abandoned as the passing of time failed to produce the expected collapse of independent practitioners (Annandale 1998; Traulsen & Bissell 2004). There is nonetheless evidence that medicine has had to accept some limitations on its power. Evetts argues that increasing state pressures toward managerialism, accountability and budget control, have significantly reduced the autonomy and power of medicine as a profession (Evetts 2003). Another example could be recent moves toward managed health care (Annandale 1998) in which, ironically, pharmacists play a significant role in limiting medical autonomy (for example in pharmaceutical benefit management).

Debates about the place of pharmacy as a profession really entered the sociological arena with Denizin and Mettlin’s (1968) seminal sociological perspective on pharmacy as an ‘incomplete profession’. Their paper identified the problems pharmacy faced, and continues to face, as lying essentially in their loss of control of their primary product, drugs. This assessment is based on Carr-Saunders’ 1933 definition of a profession as

...an occupation which is based on specialized intellectual study and training, the purpose of which is to supply skilled service or advice to others for a definite fee or salary (Carr-Saunders quoted in Denizin & Mettlin 1968:375).

This conceptualization of profession appears to contain the essential elements noted by Geisler, and remains essentially true to functionalism (Evetts 2003). It would also appear to represent the concept of professionalism against which pharmacy continues to measure itself as a profession today (Hepler 1987; SAPC 2004; Das & Das 2001; Harding & Taylor, 2002a;). The range of arguments for pharmacy as in need of re-professionalization (Brodie 1967; Birenbaum 1982; Hepler 1987; Hepler & Strand 1990; Anderson 2005) all appear to assume at least the basic elements present in Carr-Saunders’ definition. The language of South African legislation appears to be based on the same assumptions, while further reflecting the elements of control and autonomy (S.A Government 2002). While the definition does show a shift from the emphasis on altruism (which medicine can no longer lay claim to either – Armstrong 2000), it still places primary emphasis on control of knowledge and unique skill.

If it can be demonstrated that pharmacy's knowledge is no longer relevant or specialized, and the skill available to others (for example, doctors, veterinarians and nurses), then the professional status of pharmacy is open to challenge. In an impassioned plea for pharmacy to urgently take action in order to survive, Anderson records the growing range of studies and public judgements, including a formal judgement issued by a US Supreme Court justice that 'the pharmacist when dispensing a prescription, is no more professional than the "clerk who sells law books".... We are paid not for our knowledge and service but for the products we dispense' (Anderson 2005:2734).

Much of the debate about professionalization within pharmacy (and for ideological reasons, within medicine relating to pharmacy – Gilbert 2001), may well be rooted in an outdated understanding of what (or whose) knowledge is privileged, and of what 'professionalization' means. Evetts (2003) notes the growing consensus among sociologists that, certainly in the 'developed' Western world, the special nature of the concept of professions is becoming so diffuse that it appears to be on the demise. This is rooted primarily in changes in politics and economics, but also in increased access to information, and substantially improved levels of education. There is less agreement with respect to professions in so-called developing countries, where knowledge-based occupations continue to expand and be valued. It would appear that this is related to differences in the extent of access to information, and the manner in which education is gradually expanding in developing countries (Evetts 2003).

Ironically, as questions arise over the special case of the select few professions (traditionally law and medicine in English-speaking societies, religion having shifted to the periphery), the use of the concepts of *professionalism* and *professionalization* are on the increase, especially in the West:

professions are involved in birth, survival, physical and emotional health, dispute resolution and law-based social order, finance and credit information, educational attainment and socialization, physical constructs and the built environment, military engagement, peace-keeping and security, entertainment and leisure, religion and our negotiations with the next world (Evetts 2003:397).

This appears to reflect a similar pattern to the late 19th and early 20th century social challenge to old elitist definitions and dominance of the professions. This challenge once again appears to have been brought about by the emergence of 'complexity' as a result of improved communication, access to information and industrialization (Haskell in Geisler 1994), similar to that which resulted in the emergence of new 'occupational professions' noted by Geisler (1994, and above). The late 20th and early 21st centuries are dramatically

marked by further shifts in the same conceptual areas – Barnett’s age of *supercomplexity* (Barnett 2000a; 2000b) or a *risk society* (Beck and Giddens in Nettleton 1995; Annandale 1998; Traulsen & Bissell 2003; & 3.2 above). In this age the same change agents which introduced the age of complexity continue to operate, but at even greater levels of change. In a supercomplex or risk society the gaps in access to information between ‘laity’ and ‘experts’ are diminishing, expertise is increasingly regarded with suspicion, and what constitutes ‘knowledge’ is profoundly contested (Traulsen & Bissell 2003). As Hibbert, Bissell & Ward (2002), Anderson (2005), and Zellmer (2005) make clear, pharmacists are suffering just such a collapse of public confidence in their ‘expertise’.

Barnett (2000a) argues that the challenge to knowledge which characterises the early 21st century cannot be dismissed as the ‘postmodern’ agnosticism toward the meta-narrative – in fact the frameworks of what is recognised as knowledge have multiplied not vanished. For example, much to the discomfort of medicine (Prior 2003), lay knowledge is now increasingly recognised as decisive in treatment decisions (Popay, Williams, Thomas & Gatrell 1998; Hibbert, Bissell & Ward 2002; Traulsen & Bissell 2003), even if lay knowledge shares only tenuous links with biomedicine. The supercomplex world we now inhabit is characterised by ‘contestability, changeability, uncertainty and unpredictability’ (Barnett 2000a: 415). The very ability to predict, that was the hallmark of the traditional definitions of professionalism, has proven inadequate (Annandale 1998; Traulsen & Bissell 2003). As Annandale (1998:264) reflects: ‘Patients and their relatives are increasingly being made aware that medical practitioners (and other healers) do not deal in certainties; rather, there are often hard choices to be made and someone must make them. But *who* is to decide and *how* are they to do this?’

Traulsen and Bissell (2003 – following Giddens, Beck, Thompson, and Foucault) propose that sociological understandings of ‘*risk*’ offer considerable advantage for understanding the role of pharmacy specifically because they take cognisance of lay perceptions of risk. They, however, add the caveat that the meaning of ‘*risk*’ in the social theory of a ‘risk society’, especially with respect to healthcare in general and pharmacy in particular, must be carefully explained. *Risk* goes beyond the ‘technical/economic’ conceptualization which has long existed within healthcare practice (Traulsen & Bissell 2003:256), and includes macro issues of globalization, loss of trust in experts, complexity, uncertainty, risk-perception, power and politics. *Risk*, as it is now understood, is in many cases a specific consequence of the very science and technology upon which medicine and pharmacy prides itself (Traulsen & Bissell 2003).

Evetts argues that recognition of the emergence of the risk society demands a new way of understanding what it means to be a profession:

A different way of categorizing these occupations is to see professions as structural, occupational and institutional arrangements for dealing with work associated with the uncertainties of modern lives in risk societies. Professionals are extensively engaged in dealing with risk, with risk assessment and, through the use of expert knowledge, enabling customers or clients to deal with uncertainty (Evetts 2003:397 Italics added).

Her proposed conceptualization of 'profession' lends itself to a better understanding of specialized knowledge-based occupations in 21st century society. It is interesting to note how well such an understanding accords with the 'characteristics' of the pharmacy professional listed for pharmacy students in the United States:

A member of a profession who displays the following 10 traits: knowledge and skills of a profession, commitment to self-improvement of skills and knowledge, service orientation, pride in the profession, covenantal relationship with the client, creativity and innovation, conscience and trustworthiness, accountability for his/her work, ethically sound decision making, and leadership (*White paper on pharmacy student professionalism*, in Masters 2005:142 Italics added).

A major difference between the assumptions about knowledge underlying Evetts' conceptualization, and those underlying traditional understandings, could be seen as a qualitative shift in understanding of the *kind* of knowledge that is valued. Traditionally the 'body of knowledge' possessed by experts has been characterised as *practical* knowledge, and *foundational* knowledge. Evetts' inclusion of *risk* in understanding professionalism extends these to include a third kind of knowing: *reflexive* or *meta-knowing*. These three ways of conceptualizing knowledge could be distinguished as follows:

- *Practical* or *instrumental-procedural knowing* is the demonstrated ability, in an authentic context, to consider a range of possibilities for action, make considered decisions about which possibility to follow, and to perform the chosen action in accordance with established norms and procedures. It is grounded in:
- *Foundational* or *substantive-theoretical knowing* which is an understanding of the knowledge and thinking held by a specialist community that underpins and governs the action taken: and integrated through:
- *reflexive* or *meta - knowing* in which the professional demonstrates an 'ability to integrate or connect performances and decision-making with understanding and with an ability to adapt to change and unforeseen circumstances and to explain the reasons behind these adaptations' (Based on and adapted from the South African

Qualifications Authority's definition of 'Applied competence' [SAQA 2000:10] and Wells 'modes of knowing' [1999:71]).

In any consideration of 'profession' we cannot avoid the (often covert) understanding by the state of professionalization as a form of 'control at a distance' (Miller & Rose 1990, in Evetts 2003:406), nor can we ignore the concern for control and autonomy within the current conversations within pharmacy itself (SAPC 2004; Edmunds & Calnan 2001; Harding & Taylor 2002; Hibbert, Bissell & Ward 2002). Evetts' categorization of professionalism does not deny these elements, but it does focus more positively on a valued role for the professional. Evetts' focus accommodates the 'philosophy of practice' that underpins the 'pharmaceutical care' movement articulated by both Hepler and Strand (1987; 1990). Professionalism understood as Evetts proposes recognizes the knowledge to which pharmacists have access (but not control); clearly identifies a specialized role within society; and yet recognizes the agency of the patient in that the profession acts '...through the use of expert knowledge, *enabling customers or clients to deal with uncertainty*' (Evetts 2003:397 *Italics added*). Such an understanding of professionalism is congruent with the model of concordance considered above (5.1.4.1).

6.2.3 Pharmaceutical Care

[What I have to say is] based on a dream for the future of pharmacy—a dream that pharmacy will become a profession that is dedicated to helping people make the best use of medicines and that this dedication will permeate the inner fiber [*sic*] of pharmacists and shape their interactions with patients and prescribers (Zellmer 2005:259).

The urgent call for change in pharmacy as a profession, came in the 1960's from within the ranks of hospital pharmacists who challenged that pharmacy's 'servitude [to medicine] without real professional service appears to be the bulk...of the present pharmacist [*sic*]' (Autian, Berman & Guest 1963, in Hepler 1987:371). Brodie's initial call for pharmacists to establish their professional ground as those responsible for 'drug-use control' for the sake of the patient (Brodie 1967: 65), marks the first clear articulation of what Hepler (1987) termed the 'Third Wave' of pharmacy. Brodie argued that: 'Since any attempt to analyze the pharmacist's function must account for the patient's safety as well as his [*sic*] medication, one can reach a conclusion that the mainstream of pharmacy is drug-use control' (1967: 63). While little credit is given to Brodie for this, his assertion that pharmacy was concerned with drug-use control was rooted in the ethical and professional

demand that pharmacy was above all else ‘patient oriented’ and is concerned to ensure and assure the welfare of the patient (Brodie 1967:65; Hepler & Strand 1990).

Hepler’s 1987 paper receives general recognition as the landmark work with regard to the reorientation / reprofessionalization of pharmacy practice (Penna 1990; Strand, Cipolle & Morely 1992). Hepler critically confronted every facet of pharmacy from administration through education, community practice, manufacture, research and retail, with the challenge of the ‘Third wave’ of *clinical pharmacy*, which Hepler defines conceptually as ‘drug use control’ (1987:373)⁴. With a remarkable degree of perspicuity, Hepler not only identified and proposed responses to the threats to pharmacy and sources and forces for resistance to change within pharmacy, but recognised the (then) gathering storm of the information age as ushering in further, and rapid, changes for the profession. Central to these changes would be patient care, and the need for the re-integration of practice and education (Hepler 1987).

Pharmacy’s struggle for identity has influenced the way it has developed its ‘philosophy of practice’ – the way the pharmacist relates to the patient (Birenbaum 1982; Hepler 1987; Turner 1987; Strand, *et al.* 1992; Gilbert 2001). The ‘philosophy’ of *pharmaceutical care* commonly linked to Hepler & Strand (1990), is to a large extent an evolution of Hepler’s earlier thesis of ‘clinical pharmacy’, which he argued is the basis for the ‘reprofessionalization’ of pharmacy (Hepler 1987:374; Posey 1997). Birenbaum (1982) shares the perception that the turn to clinical pharmacy reflects a move toward reprofessionalization. Despite Holloway *et al.*’s (1986) objection to this as ‘meaningless’, the reprofessionalization of pharmacy is invariably linked, in both pharmacy-based and sociological literature, to the shift towards ‘patient centred’ discourse and pharmaceutical care (Hepler & Strand 1990; Posey 1997; Edmunds & Calnan 2001; Traulsen & Bissel 2001).

However we conceptualize the reasons for the advocacy of pharmaceutical care, there is no doubt that since the 1960s there has been a strong call for pharmacy practice to be informed by this, and related concepts (drug-use control, clinical pharmacy, therapeutic alliances, and recently ‘concordance’). While there are a range of definitions of pharmaceutical care (Lubbe 2000), the evolving definitions offered by Hepler (1987),

⁴ Although Hepler has largely been hailed as the originator of the concept, he acknowledges that he is indebted to Brodie (1967) with respect to the concept behind clinical pharmacy, drug use control (Hepler 1987:373; Posey 1997).

Hepler and Strand (1990) and Strand, *et al.* (1992), form the basis for the most common variations (Lubbe 2000: 15 – 30). Hepler originally described pharmaceutical care as:

a covenantal relationship between a patient and a pharmacist in which the pharmacist performs drug use control functions (with appropriate knowledge and skill) governed by an awareness of and commitment to the patient's interest (1987:376).

Five years later, the definition offered by Strand, *et al.* captures the essence of pharmaceutical care as drug information and management, within the context of a pharmacist's interaction with a patient. Significantly however, the key element of the covenantal relationship between the pharmacist and the patient has already been diluted:

Pharmaceutical care is that component of pharmacy practice which entails the direct interaction of the pharmacist with the patient for the purpose of caring for that patient's drug-related needs.... We agree with Hepler and Strand that "pharmaceutical care is the responsible provision of drug therapy for the purpose of achieving definite outcomes that improve a patient's quality of life" (Strand, *et al.* 1992:6 Italics in original).

Hepler (1987), Hepler and Strand (1990), and Strand, *et al.* (1992) are at pains to stress that pharmaceutical care is *intended* to be a patient-centred, and not a product-centred approach. However, as a practice-focussed model, pharmaceutical care has been reduced to a seven- or nine- step process. Significantly the step that has most obviously been omitted from some of the South African models, is the first. Table 6-ii below compares the model used to evaluate the level of pharmaceutical care in South African pharmacies by Lubbe, Serfontein, Futter and Steyn (2001:13), with that proposed by Strand, *et al.* (1992).

Lubbe, Serfontein, Futter and Steyn	Strand, <i>et al.</i> (Italics added)
	1. <i>Establish the pharmacist-patient relationship: Make contact with and commitment to the patient.</i>
1. Collection of essential medical and medication information from patients to assess the appropriateness of patient's drug therapy.	2. Collect, synthesize, and interpret the relevant information: Determine necessary patient, drug, and disease data – interpret as pharmacist with the patient.
2. Assessment of the patient's drug-related needs to identify drug-related problems.	3. List and rank the patient's drug related problems: Define and prioritize actual and potential drug-related problems.
3. Development of a care plan (monitoring plan) for each identified medical problem to ensure that the drug therapy meets its therapeutic goals.	4. Establish a desired pharmacotherapeutic outcome for each drug-related problem: For each problem needing resolution or prevention, determine with the patient the desired outcome – quantitative and measurable.
4. Identification and resolution of drug-related problems.	5. Determine feasible pharmacotherapeutic alternatives: List those therapeutic modalities that could achieve the desired outcome in this patient.

5. Follow-up evaluation (personally or telephonically) of each patient's medical conditions to determine progress towards meeting the established goals of the drug therapy by evaluating the actual outcomes a patient experienced against these stated goals.	6. Choose the "best" pharmacotherapeutic solution and individualize the therapeutic regimen: With the patient, decide the best drug, dose, formulation, regimen, schedule etc.
6. Follow-up evaluation (personally or telephonically) to assess whether any new drug therapy problems have developed or whether any new drug therapy problems need to be prevented in the future.	7. Design a therapeutic drug-monitoring plan: Develop a plan to determine whether the desired therapeutic outcome has been achieved – plan must include monitoring for adverse effects.
7. Documentation of activities associated with the care of the patient.	8. Implement the individualized regimen and monitoring plan: With the help of the patient and the health-care professionals responsible for the patient, implement and document the decisions made.
8. Provision of written summary of all the medication the patient is currently taking as well as the care plan that was developed for the patient	9. Follow up to measure success: Determine the pharmacist's success on an individual patient basis and on a long term basis

Table 6-ii: Examples of pharmaceutical care models (Lubbe, Serfontein, Futter & Steyn 2001:13 and Strand, *et al.*, 1992:15. Italics added)

While the discourse of Strand *et al.*'s process is not unproblematic, and presents an already diluted form of Hepler's 'covenantal relationship', it nonetheless evidences a more explicit commitment to patient-centeredness than the pharmacist- / product- centred practice evaluation apparent in Lubbe *et al.* (2001).

The South African Pharmacy Council clearly places pharmaceutical care at the core of the philosophy of pharmacy practice (SAPC 2004; Lubbe, Serfontein & Lamprecht 2003). The SAPC's understanding of pharmaceutical care bears a resemblance to Strand *et al.*'s (1992) usage, however it does reflect a more pharmacist-centred approach, defining pharmaceutical care as the pharmacist's '*taking responsibility for the outcome of therapy and by being actively involved in the design, implementation and monitoring of pharmaceutical plans*' (SAPC 2004:2 Italics added). This understanding remains rooted in compliance discourse, and lacks the patient-centeredness which pharmacy claims as a defining feature. The absence of emphasis on the clinical relationship between pharmacist and the person seeking assistance (see 2.2.2.3 & 5.1.4 above), is effectively missing.

Rather than a *philosophy* of pharmacy, the model of pharmaceutical care proposed in South Africa (IPCSA 1998; Lubbe, Serfontein, Futter & Steyn 2001) appears, at best, to be a *procedure*, a step-by-step method, and one in which relationship with the patient becomes lost in quality assurance and efficiency. Indeed Futter, despite a strong emphasis on establishing a 'trusting relationship with the patient' (2002a:79), has designed an 'Integrated model of pharmaceutical care' (to guide practice at both individual and community level), which he describes as a 'management process based model...which is

based on quality assurance principles' (2002a:65). The discourse of Futter's 'integrated model' reflects the *patient*-centred perspective of the old BPSM, rather than the *relationship*-centred practice of the BPSP (see above 2.2.2.3). This perspective is emphasised by his usage of 'Compliance' as one of the risk assessment areas in assessing drug related problems (2002a:73). While Lubbe *et al.*'s (2001) usage does stress one element of Hepler's usage of 'covenantal' ('that professionals accept responsibility rather than merely provide functions' – Hepler 1987:276), they gloss over Hepler's insistence that a professional covenantal relationship must 'transforms both parties' (May 1975 in Hepler 1986:375) and avoid 'cold, limited contact...[or]... philanthropic condescension' (1987:375). These examples of South African understanding of pharmaceutical care appear incompatible with a new understanding of professional pharmacy practice aligned with Evetts' (2001) conceptualization of 'professional' in a risk society. Most significantly they fail to acknowledge patient agency, and do not reflect the core element of a *covenantal relationship with a patient* (and/or her/his care-giver), that is a fundamental requirement for pharmaceutical care (Hepler 1987:376; 2000).

The failure to retain the 'covenantal relationship', and simply to reduce it to 'taking responsibility for the outcome of therapy', reflects something far more fundamental than mere semantics: it becomes a matter of semiosis ('semiosis is the making of meaning through recourse to language and other semiotic systems' – Fairclough, Jessop & Sayer 2002:6). The way pharmacists *make meaning* of their profession, depends in part on how they understand the context of their professional praxis (practice-reflection). Hepler's usage of 'covenantal relationship' is rich and, while based on a particular understanding of professional which has been challenged (see 5.2.2. above), needs urgent reconsideration in the light of the challenges to pharmacy in South Africa.

Hepler (1987:375 – 376) argues that there are two basic elements of a 'covenantal relationship': *competence* and *authority*. These, he argues, involve not only the pharmacist and an individual client/patient, but also the pharmacist and society, and pharmacy and society. Within the context of the client/patient relationship, both pharmacy and pharmacist are involved in the 'exchange of a promise and a gift' which forms the basis of a covenant (Hepler 1987:375). The 'promise' that the pharmacist presents is the pledge of *competence*, the 'knowledge and skill to perform a particular function, and an attitude of commitment to the client's value interests' (Hepler 1987:375). The gift within this covenant, is given by the patient. In direct contrast to the business relationship of *caveat emptor* (let the buyer beware), the gift of *authority* given by the client/patient, grants the professional status of

caveat vendor ('let the seller take care') to the pharmacist. Ironically it is the very 'helplessness' of the client/patient that transforms the pharmacist into a professional, by demanding that the professional must have a 'commitment to client welfare' (Hepler 1987: 376). Hepler argues that it is pharmacy's failure to understand the nature of this covenantal relationship, and especially the nature of the social and cultural understanding of the 'gift of authority', that has led to pharmacy's virtual exchange of professional relationship, for a business relationship (1987: 375 – 6). Even recent statements of and on pharmaceutical care, while they re-iterate patient-centeredness, focus on the promise of competence and cooperation with other professionals (FIP 1998; Tanna 2002). The patient, however, recedes as anything other than a passive recipient who, having once granted the gift, 'now is done unto her'.

What may now be in question is the nature of the *competence* that the pharmacist offers, and the nature of the *authority* granted by the client/patient. Hepler's original understanding of competence was wider than merely access to information ('facts') and/or skills, going beyond these to include attitudes (1987). The South African understanding of competence (outlined above 5.2.2.) extends Hepler's demand of *practical* and *foundational knowing* (which together appear to characterise the 'body of knowledge' possessed by experts), and requires the further element of *reflexive knowing* (above 3.1.2; 5.2.2.). Hepler's understanding must therefore be extended to explicitly include *reflexive knowing*, which is congruent with the concept of 'mindfulness' proposed by Borell-Carrió *et al.* (2004 & above 2.2.2.3). In the case of *authority* granted to the pharmacist by the patient, such authority no longer has the force of 'doctor's orders' as Hepler suggests (1987:375), but as with all professional authority, is balanced by client/patient knowledge and access to information, and rests on trust. It presupposes a move from compliance to concordance.

Trust is 'rooted in the patient's judgement that the provider will act in her best interests' (Gilson, Palmer & Schneider 2005:2). Built on both structural and individual levels: trust is in part based on the client/patient's experiences of trusting similar professionals, the specific professional, and their individual experiences of trust in life. Trust is, however, extremely fragile, and trust built up over time can be destroyed in a single incident (Illingworth 2002; Gilson, *et al.* 2005). Although not referring to 'trust' explicitly, Hepler (1987) argued that one element of the authority that society grants to a profession, lies in the profession's 'power to protect society's interests' (Hepler 1987:375). This power rests in part on the quality and nature of pharmacy education (Hepler 1987; Gilson, *et al.* 2005).

Thomasama (1983:247) proposes six ethical axioms on which a healthcare practitioner's prudential judgement (mindfulness) must rest, and which, with adaptation, can inform the professional authority upon which trust is placed. The six axioms were originally proposed for medical doctors, and based on the assumption of the priority of 'benefice', understood to mean 'for the good of the patient' (Thomasama 1983:246). This assumption cannot be uncritically adopted for pharmaceutical care in the 21st century, with the concept of beneficence rooted in an essentially paternalistic ('weak paternalism' – Thomasama 1983:245) approach which assumes, among other things that a sick person of any age, does not have the right to choose to refuse what the practitioner considers life-sustaining treatment (1983:245). With this caveat in mind, my adapted version of Thomasama's (1983:247) ethical axioms, which could underpin the professional competence of a pharmacist with respect to a therapeutic relationship with a patient are:

1. **Both pharmacist and patient must be free to make informed decisions.** Because of a necessity to reach consensus and to respect the values of both pharmacist and patient, both pharmacist and patient must be accorded the freedom to express their values, and must enjoy both sufficient information and freedom from coercion.
2. **Pharmacists are morally required to pay genuine attention to patient vulnerability.** The asymmetry of power inherent in the pharmacist's professional expertise and access to information, must be corrected by conveying honest and balanced information to support the patient in making decisions about their medicine practice.
3. **Pharmacists must use their power responsibly to care for the health-related needs of the person with whom they are engaging.** Because the asymmetry of power is inherent in the need of the sick person for access to the resources provided by the pharmacist, the pharmacist must use such power to restore autonomy to the person in as far as this is possible.
4. **Pharmacists must have and act with integrity.** The demand to exercise 'prudential judgement' (mindfulness) in every dealing with a patient (and any caregiver), requires that the pharmacists' actions (including inaction) must be informed by professional and ethical considerations.
5. **The pharmacist must understand and respect moral ambiguity.** In an age of supercomplexity, pharmacists must beware of the temptation to apply problem-solving algorithms and/or formulaic procedures, to bring closure to a dilemma involving patient care.

If pharmacy education is to prepare students for the challenges of professional practice in the 21st century, then a commitment to a more informed understanding of the nature of their practice is imperative. In the light of shifts in understanding of professionalism during the eighteen years since Hepler proposed this understanding of pharmaceutical care, I propose an understanding based on the work of Hepler (1987), Strand *et al.* (1992) and Hepler and Strand (1990), and aligned with Evetts' (2003) understanding of professionalism, that may serve to acknowledge both the agency of the patient, and the socio-cultural basis for the praxis of drug-related therapy:

Pharmaceutical care is the philosophy of practice of a covenantal relationship between the pharmacist and a patient and, where relevant, caregivers and other healthcare practitioners, for the purpose of caring for that patient's drug-related needs. The goal of pharmaceutical care is the responsible provision of advice on, and drug-related therapy for the purpose of, achieving and sustaining an optimal improvement in a patient's health related quality of life.

6.2.4 Pharmaceutical care in South Africa

Although South African pharmacy practice, especially retail and community pharmacy practice, could really benefit from the adoption of pharmaceutical care (Gilbert 1998), and despite the SAPC's clear commitment to pharmaceutical care, this practice philosophy does not appear to have permeated to the majority of pharmacists in South Africa (Lubbe, Serfontein, Futter, Steyn, & Serfontein 2000). Pharmaceutical care 'requires changes in various areas of the current approach and practice situation' (Lubbe *et al.* 2003:8). Gray & Bodley Smit (1998) contend that the problem lies in the lack of qualified staff, but as indicated previously, there appears to be a more prosaic problem, which in some way illustrates the philosophical difficulties underpinning the professional status of pharmacy mentioned earlier: the clash between business-for-profit and altruistic service. In response to a 2000 – 2001 survey, South African pharmacists indicated that the lack of financial incentive was the 'most important [barrier] to the implementation and provision of pharmaceutical care in South Africa' (Lubbe, Serfontein, Futter & Steyn 2001:12). This reflects the concerns expressed by Hepler with respect to community pharmacy 'reimbursed on the basis of product sold, not labor [sic] and drug cost' (1987:377). It is of course precisely the source of the pharmacist's reimbursement, that is central to the current struggle around medicine-related legislation in South Africa. This legislation, while highly problematic (Thom 2005), presents an opportunity for community pharmacy to investigate a professional model of pharmaceutical care practice, as opposed to a business model of drug distribution.

Lubbe, Serfontein, Futter, Steyn, and Serfontein (2000) suggest that South African pharmacists are either not aware of the underlying philosophy of pharmaceutical care, and view it as a simple algorithm, or they have chosen to disregard the more demanding elements of pharmaceutical care to avoid conflict with the medical profession, or because of the lack of incentive. Significantly, and to some extent in contradiction to the 2000 – 2001 survey, Lubbe *et al.* (2000) found that South African pharmacists were generally of the opinion that they *were* providing a professional service of pharmaceutical care. Medical aid organisations, however, were less certain that this was so, indicating that the following fundamental elements of the pharmaceutical care process appear to be missing more often than not (Lubbe *et al.* 2000:9):

- collection of essential medical and medication information;
- assessment of patients' drug related needs;
- development of a care plan;
- identification, resolution and prevention of drug therapy problems;
- follow-up evaluation of each of the patient's medical conditions.

As Lubbe *et al.* (2000) note this perception could be because medical aid organisations are unaware of the work that pharmacists actually do. While this may be a factor, it would suggest that the documentation process integral to pharmaceutical care is not being followed through and, more significantly, there should have been evidence of changes to regimens that should have been pharmacist-initiated.

Implementing pharmaceutical care as a philosophy of practice is clearly not without difficulty. Lubbe (2000:72) lists five factors militating against the acceptance of pharmaceutical care in South Africa (Table 6-iii):

Negative factor / barrier	Description
Attitudinal	• pharmacists' resistance to change; ○ lack of understanding of what is expected ○ lack of competence for new role(s) ○ threatened professional status of pharmacy • attitudes of patients ○ resistance to spending time in pharmacy ○ resistance to added costs ○ concern about medical territorial issues • attitudes of other healthcare professionals ○ territorial disputes ○ lack of awareness of pharmacists' capability • attitudes of third-party payers (medical aid organisations) ○ lack of awareness of pharmaceutical care ○ concern about costs ○ resistance to challenge to authority

Educational	• lack of research which meets the traditional criteria for acceptance • lack of therapeutics and / of clinical problem solving skills • failure to recognise the importance of the role • inadequate communication skills • inadequate documenting skills • failure on part of academic institutions to value pharmaceutical care
Profession related	• weak and unsupportive professional relationships • lack of support for concept from professional bodies (not in SA)
Resource related	• lack of time (customer pressure; numbers) • inadequate facilities for privacy • lack of clear cost-benefit analysis for pharmaceutical care
System related	• lack of management support • lack of financial incentive • fragmentation of health care system

Table 6-iii: Factors militating against pharmaceutical care (Lubbe 2000: 7 - 8)

The distinctions made by Lubbe seem at times somewhat artificial, but three threads appear to dominate: those related to *professional identity* (including relations with other professions, patient attitudes, financial incentives); *education* (both initial and professional development); and what they term *system related* (resources; professional territorial conflicts; state intervention; fragmented healthcare system). I would nonetheless argue that at root these rest on pharmacy's tenuous professional identity, which continues to exhibit the failure to understand the nature of covenantal relationship suggested by Hepler (1987).

As I have noted, Gray and Bodley Smit (1998) argue that the lack of qualified staff is one of the biggest challenges facing the implementation of pharmaceutical care in developing countries. Addressing this will require new approaches to pharmacy education which will 'build problem solving skills and flexibility, and socialize students in a manner that reflects a commitment to the philosophical bases of the profession [viz. pharmaceutical care]' (Gray & Bodley Smit 1998:460). The World Health Organisation (1993), the FIP (2000) and the Interim Pharmacy Council of South Africa (IPCSA:1998) prioritise the need for educational preparation for pharmaceutical care. The FIP statement is unreserved: 'Educational programmes should ensure that patient-focused pharmaceutical care...is a mandatory part of the curriculum' (FIP 2000: 3, Recommendation 2). What is missing in these appeals, however, is the need to re-conceptualize pharmaceutical care as relationship-centred. The problem then becomes: what form must these new approaches to education take, so as to support a strong understanding of pharmacy as the profession of pharmaceutical care?

The following chapter briefly explores the landscape of pharmacy education, narrowing this down to the curriculum in place in the Faculty of Pharmacy at Rhodes University, South Africa, the context in which this study is situated. I then go on to propose a pedagogic approach which is practically applicable within the demanding curriculum load, but is underpinned by theoretical perspectives outlined above, and thus provides a response to the challenges set out by Robinson (2000) and Traulsen & Bissell (2003). One model of the proposed approach is then illustrated in Chapter 8 in an account of the fourth year 'Medicine-taking and chronic illness' elective, offered in the Faculty of Pharmacy at Rhodes University during 2004.

Chapter 7 : Teaching and Learning to promote Epistemological Access

[Professional] schools of contemporary research universities give privileged status to systematic, preferably scientific, knowledge. Technical rationality, the schools' prevailing epistemology of practice, treats professional competence as the application of privileged knowledge to instrumental problems of practice. The schools' normative curriculum and separation of research from practice leave no room for reflection-in-action, and thereby create – for educators, practitioners, and students – a dilemma of rigor or relevance (Schön 1987:xi).

[L]earning involves not only becoming a member of a community, not only constructing knowledge at various levels of expertise as a participant, but also taking a stand on the culture of one's community, in an effort to take up and overcome the estrangement and division that are consequences of participation. Learning entails both personal and social transformation (Packer & Goicoechea, 2000: 3).

7.1 Introduction

The pharmaceutical care movement grew out of the experience and practice of clinical pharmacists operating in hospital settings. The earliest formal articulation of pharmaceutical care can be traced back to an address to the American Association of Colleges of Pharmacy, and the subsequent publication of an expanded version of that address (Hepler 1987; Posey 1997). The very Achilles heel of pharmacy as a profession – the fact that it behaves as a business for profit – is reflected in the location of the seminal figures in pharmaceutical care, not in academic or retail pharmacy, but in hospital pharmacy, beginning with Brodie in 1967, Hepler in 1985 & 1987, and the team of Strand, Cipolle and Morley during the late 1980's (Posey 1997). While the influence of hospital pharmacists provided the clinical emphasis in pharmaceutical care, relying strongly on pharmaceuticals, it was pharmacy education that Hepler hoped would provide the setting for the transformation of pharmacy as a profession (Hepler 1987).

As indicated previously, I will begin this chapter by considering the wider landscape of pharmacy education. This brief overview will begin with a glance at the global context, then narrow down to the curriculum of the Bachelor of Pharmacy, in the Faculty of Pharmacy at Rhodes University. I will then outline the theoretical background to support a pedagogic approach which could be used within a pharmacy curriculum to support the

development of *reflexive competence*, with respect to pharmaceutical care and people living with chronic illness.

Using the pedagogic theory presented below, and with reference to the rest of the Rhodes University Pharmacy curriculum, in particular Pharmacy Administration and Practice, the following chapter (Chapter 8) will present a practical illustration of one pedagogic model to support pharmacy students' *epistemological access* (see below 7.2.1.) to the experience of chronic illness. This will be done through a consideration of the fourth year elective ('Medicine-taking and chronic illness') which I offered in the Faculty of Pharmacy at Rhodes University during 2004.

7.1 *The pharmacy education landscape*

The struggle for social / professional identity and legitimization has inevitably influenced, and been influenced by, pharmacy education's location within the university, a situation common to professions as knowledge occupations (Hepler 1987; Schön 1987; Geisler 1994; Evetts 2003). As pharmacy entered what Hepler terms 'The science era (1940 – 1970)', pharmacy education found itself conscripted in the battle for professional identity. As the focus of pharmacy shifted from Galenical methods, to physics and chemistry, so pharmacy education underwent a shift from 'descriptive empirical teaching disciplines into organized scientific paradigms' (Hepler 1987:370). Hepler points to a significant consequence of this scramble to gain scientific credibility: curriculum support for pharmacy practice with its concern for the relationship and interaction between pharmacist and patient, was so severely undermined that in many cases it disappeared:

The pharmaceutical industry, interested in developing and selling drug products, naturally encouraged research oriented around the drug product. This helped advance the scientific legitimization of pharmaceutical education. Unfortunately, there is no comparable source for the development of pharmaceutical services. Like a tree growing with only one side in the sun, pharmaceutical education became asymmetricalpharmaceutical education seemed to lose sight of its purpose....Faculty may have imagined that the methods that were legitimizing pharmacy faculties in the University were somehow to legitimize practitioners in the drugstore. Unfortunately, society did not seem to need a scientist on every streetcorner [*sic*] (Hepler 1987:370).

In a 'state of pharmacy' overview undertaken in 2002, Anderson provides a summary of North American, British and European pharmacy curricula, which are still weighted towards the sciences (Table 7-i):

Subject	Description
Pharmaceutical chemistry	Study of the chemistry of medicinal substances including their synthesis and analysis
Pharmacology	Study of the actions and uses of medicines including absorption, distribution and excretion from the body
Pharmaceutics	The conversion of medicinal substances into suitable dosage forms such as tablets, injections and inhalers
Pharmacognosy	The study of medicinal substances of natural origin
Social and administrative pharmacy	Study of the social, political and economic aspects of the use of medicines
Forensic pharmacy	The law in relation to medicines and pharmacy

Table 7-i: The pharmacists' education: core pharmaceutical subjects (Anderson 2002:35)

The duration and levels of the required qualifications for practice vary greatly, ranging from three to six years, with most including at least six months of practical experience prior to registration (Anderson 2002). In 1998 the South African Pharmacy Council (then the Interim Pharmacy Council of South Africa – IPCSA) developed the entry level qualification requirements according to the then Department of Education's requirement for all curricula to be written in a rigid Outcomes Based Education format, as 'Unit Standards' (IPSCA 1998) (Table 7-ii). This document describes the seven overall competencies required of any 'entry level' pharmacist (i.e. a pharmacist entering the profession having completed both four year degree and one year's internship). According to the IPCSA 'Pharmacists entering the profession must be able to...':

UNIT EL1	Organise and control the manufacturing, compounding, and packaging of pharmaceutical products
UNIT EL2	Organise the procurement, storage and distribution of pharmaceutical materials and products
UNIT EL3	Dispense and ensure the optimal use of medicines prescribed to the patient
UNIT EL4	Provide pharmacist initiated care to the patient and ensure the optimal use of medicine
UNIT EL5	Provide education and information on health care and medicine
UNIT EL6	Promote community health and provide related information and advice
UNIT EL7	Participate in research to ensure the optimal use of medicine

Table 7-ii: Entry Level Qualification Unit Standards for South African Pharmacists (IPSCA 1998:3)

Being a competency-based curriculum model, the Unit Standards do not prescribe content, 'subjects' or disciplines. Generally the South African pharmacy departments' offerings reflect the disciplinary list given by Anderson (Table 7-i). In addition all five offer specific

courses (mostly one year in duration) in anatomy and physiology. The Bachelor of Pharmacy degree offered through the Faculty of Pharmacy at Rhodes University, begins with a general science first year (Biology, Chemistry, Mathematics, Physics, Statistics, and an introductory Computer Science course), before continuing into three years of the pharmacy specific courses noted by Anderson (Table 7-i). One difference between the Rhodes' offering and those of other South African universities, is that pharmacokinetics (on which Therapeutic Drug Monitoring [TDM]– the clinical core of pharmaceutical care – is based) is located in Pharmaceutics, rather than in Pharmacology (Table 7-i). TDM is explicitly linked to Pharmacy Administration and Practice (PAP), the Rhodes equivalent of Social and Administrative Pharmacy (Rhodes University 2005: 94 – 96).

With the possible exception of social and administrative pharmacy or its equivalent, such curricula have remained essentially unchanged since the 1970's (Hepler 1987; Ritschel 1992). Referring to a curriculum still familiar today, with pharmacology having finally achieved acceptance after fifty years of struggle in 1953, followed by pharmaceutical chemistry, Hepler challenges that by the 1970s pharmacists had become 'over educated and underutilized' (1987:371). Hepler's critique bears strong similarities to Schön's criticism (above):

For all its progress, [pharmacy] education seemed to have lost its purpose of producing professionals. It had compartmentalized its curricula along disciplinary lines and seemed to have replaced the objective of educating professionals with the typical objectives of liberal arts and science faculties: discipline-oriented teaching, peer relationships, publications and external funding.... A science-profession duality complicated the old business-profession duality, further blurring pharmacy's already vague outline (Hepler 1987:371).

Ending his overview of the 'Scientific era' of pharmacy, Hepler laments that 'In legitimizing itself academically, however, pharmaceutical education had isolated itself from practice' (Hepler 1987:371).

To facilitate the reprofessionalization of pharmacy, Hepler advocated a new pharmacy curriculum, placing emphasis on the study of pharmacokinetics, which had emerged as a core knowledge area of clinical pharmacy in the 1970s (Hepler 1987; McLoed & Miller 1981). Education's contribution to reprofessionalization, he argues, can be summarised under four headings. Education must:

- a) 'provide research, scholarship, and teaching about the nature of the profession's relationship to society';

- b) 'address the cognitive and attitudinal barriers to asserting authority and accepting responsibility...[through]...problem solving...but research is needed into pharmacy's *willingness to assert cultural authority*' [Italics added];
- c) 'address pharmacy's effectiveness in drug use control' [which he unpacks at some length later in his paper, with respect to new models of community and clinical pharmacy];
- d) 'devise methods of evaluating the competence of students in all three dimensions (knowledge, skill and attitude) and modify its processes based on these evaluations' (Hepler 1987:376).

The challenge to pharmacy education is re-stated by Strand, *et al.*, who call for pharmacy faculties to 'redesign our educational programs to prepare the next generation of pharmaceutical-care practitioners' (1992: 30). Several years later Droege (2003), and Traulsen and Bissell (2004) argue for substantial shifts in both content and pedagogic practice in pharmacy education, in order to enable pharmacists to place pharmaceutical care at the centre of their practice.

If practicing pharmaceutical care requires a shift in focus from drug product to patient, so does teaching future practitioners. The curriculum would have to address issues that go beyond didactic and experiential courses; it would also have to include environmental, cultural, and social components that can help to build a new conceptual framework of a professional practice (Droege 2003:72).

What pedagogic approach toward pharmacy practice education could support the competencies, attitudes and values required of a pharmaceutical care professional? The FIP recommends that 'Teaching and learning should be student-centred. *Educational philosophy, structures, outcomes, methods and context should be considered of equal importance to content of syllabus*, and should be subject to evaluation' (FIP 2000: 4, Recommendation 9 Italics added). The FIP further outlines seven identified roles and responsibilities of the pharmacist (care giver, decision maker, communicator, leader, manager, life-long learner and teacher), fundamental to which are the core competences of a reflexive practitioner: integration of knowledge and values into problem solving and critical thinking (FIP 2000: 2 & 6). Droege argues convincingly for the urgent need to adopt a pedagogic approach focused on developing pharmacists as 'reflective practitioners':

Ways of learning change over time, in that novices, lacking expertise and experience, need to rely more on proposition knowledge and rules

of thumb. The focus of education in pharmacy, at all stages, has tended to be on proposition (written) knowledge, on memorizing facts rather than taking responsibility for one's own learning and the realities of patient care. However, models such as Schön's reflection-in-action embrace an integrated model of acquiring knowledge and can be seen as an important way for pharmaceutical care practitioners to make the best use of their knowledge and advance their skills (Droege 2003:73).

7.2 Learning and Teaching in an age of *supercomplexity*

'Post-modernism', '*risk*', '*supercomplexity*', are all descriptions of the 'age' in which pharmacy students must now prepare to work. In essence these descriptions, although reflecting different theoretical perspectives, describe a world which is open and indeterminate, and at variance with the reductive approaches of biomedicine (Gwyn 2002; Droege 2003; Grumbach 2003). I have noted some of the implications of living in the risk society for healthcare (3.2), and referred briefly to Barnett's concept of *supercomplexity* (3.2). The concept of *supercomplexity* has been well-developed within the debates around the higher education curriculum (Barnett 2000a, b, c), but Barnett's description of *supercomplexity* intersects remarkably with the picture of chronic illness as a 'loss of "the destination and map"...' which guided peoples' lives (4.4.1, above). Indeed, in many ways 'our *supercomplex* age' (below) could be substituted by 'chronic illness' and the description would retain a poignant validity. As noted above (3.2), Barnett describes *supercomplexity* as marked by:

...contestability, changeability, uncertainty and unpredictability...
These four concepts are surrounded by others such as change, turbulence, risk and chaos. Together, this set of concepts mark out the conceptual geography of our *supercomplex* age as an age of fragility...
It is an age in which nothing can be taken for granted. In short, all bets are off. It is an age of conceptual and, thereby, emotional, insecurity (Barnett 2000a: 415 – 416).

Chronic illness, as we noted, is increasingly a feature of illness experience in late modernity – the same age to which Barnett refers. A pedagogic approach which takes *supercomplexity* into account, may well provide a basis for preparing healthcare professionals to support those who live in the *supercomplex* experience of chronic illness.

7.2.1 *Supercomplexity and (university) education*

Barnett has thoroughly described supercomplexity and linked the perspective to higher education and the curriculum (2000a, b, c). What follows will necessarily be a select summary.

Supercomplexity describes an age in which the frameworks which we use to understand the world, the conceptual ‘meta narratives’, are viewed and challenged as contestable. So I noted how difficult it was to agree on understandings of concepts basic to the pharmacists’ practice, such as: health, disease, illness and sickness. Finding a place to stand in order to *understand* is increasingly difficult. So, in words which once again evoke a sense of the experience of living with chronic illness, Barnett asks:

Do we embrace science or mistrust it? Do we hang on to the welfare state or, instead, look to individuals to take responsibility for themselves? Do we abandon religion or seek to welcome new religions? ... How do we apportion relative priorities between freedom, justice, responsibility and equality? Does social change spell social progress? Is science a force for increased rationality and control or is it an ideology serving particular interests? ... And so on and so on (2000a:75).

One of the consequences of this, is that it is professionals, whose social / occupational identity is so tied to knowledge, that find themselves most at sea in the age of supercomplexity (2000a).

What then is the educational responsibility of the university in the face of this? Barnett proposes three fundamentals which he refines in various ways throughout his project:

1. to participate in generating, interrogating, and informing society about, supercomplexity;
2. to help us develop compelling narratives about the world (and ourselves);
3. to enable us to develop a sense of self and others that will enable us to live constructively within society ‘*and such that we can make purposeful but **reflexive** interventions in the world*’ (Barnett 2000a:77 Italics in original, emphasis added).

In these three tasks, an analytical dualism appears with respect to the core functions of the university: research in many ways *generates* (or at least is complicit in generating) supercomplexity, and teaching ‘becomes the management of the human relations of supercomplexity’ (Barnett 2000a:79). In this sense, supercomplexity once again reflects a close relationship with the care of people living with chronic illness.

7.2.2 *Supercomplexity and teaching*

There is a danger here that teaching and learning may appear futile: if all frameworks are contested, what is the pedagogic responsibility of education in the university? Linked to the three points noted above, Barnett (2000a: 154) proposes:

Firstly, it has to create epistemological and ontological disturbance in the minds and in the *being* of students: it has to pose cognitively and experientially the radical uncertainty presented by supercomplexity [to which I would add for this study, chronic illness]. Students have to come to *feel* in every sense the utter insecurity of the post-modern world. Secondly ...[it]... has to enable students to live at ease with this perplexing and unsettling environment. Thirdly, it has to enable them to make their own positive contributions to this supercomplex world, while being sensitive to the unpredictability and uncontrollability of the consequences of what they say and do (Italics in original).

Pedagogy, then, has to develop an element of ‘radical uncertainty’ which reflects the supercomplex age (Barnett 2000a:154). Clearly this involves not merely some Cartesian engagement with students’ cognitive certainties, but also their *affective* assurance, or to use Barnett’s phrase: ‘their *being*’ (2000a:155). It also involves human praxis on and in the world (including society), and an understanding of agency that is *not* determined. Here links to Archer’s (1995, 2000; 2002; 2003) development of personal and social identity through reflexivity can be made. The openness and indeterminateness of the social world noted by Barnett, is further underscored by Archer: ‘Society is that which nobody wants, in the form in which they encounter it, for it is an unintended consequence’ (1995:165).

Clearly for the student (and for society) education must go beyond unsettling the student and then enabling her/him to feel better about that. This is most definitely the case with respect to healthcare professionals – society expects, and pharmacists must ‘do their duty’. Barnett’s third act in the responsibility of education is thus ‘enabling students, as graduates, to act purposively in the world’ (2000a:155). What must then be the nature of this ‘purposive act’? Once again there is serendipitous alignment between the language Barnett uses, and the particular orientation of pharmacy: firstly ‘the action should be beneficial in its intentions.... [and]...conceptually connected with an espoused framework or set of frameworks ... [but such framework] ... should also contain some ethical anchoring’ (Barnett 2000a:156).

The second dimension of the ‘purposive act’ relates to the engagement with the student’s *being* alluded to above. University education in general, and pharmacy education in

particular (see the criticisms of pharmacy education noted by Traulsen & Bissell and Droege), have avoided such affective engagement, despite the nod to the inadequacy of propositional knowledge alone that is implicit in involvement of students in 'professional or community experience' (Barnett 2000a:157). University education has, covertly at least, acknowledged that 'The epistemological gap between formal knowing and acting can only be bridged, if at all, through taking the plunge, through personal commitment to and in presenting situations' (Barnett 2000a:157). Barnett argues that the pressures of supercomplexity (with its multiple interpretive frameworks) are acutely present in today's professional / client relationships, and education based on propositional knowledge is inadequate for such a context. Education for a supercomplex world must:

...recognize the three domains of knowing, self-identity and action as irreducible to each other. Accompanying these domains are three elements: communication, emotion and a sensitivity to the ethical.... Of the first three, self-identity is gained through one's knowing efforts and in one's attempts to act in the world (Barnett 2000a:157).

The development of reflexivity must become a fundamental component of higher education, as graduates must be able to 'contest' and 'confront' changing conceptual frameworks in action (Barnett 2000a 158).

Barnett argues that pedagogic engagement with supercomplexity must reflect the 'uncertainty, unpredictability, contestability and challengability [*sic*]' of the age. The kind of reflexivity required for professional practice cannot be developed in contexts of certainty. University pedagogic practice must 'focus on the student's being and...produce the challenges of coping with uncertainty.... The necessary transformation of the student's being requires nothing less' (2000a:159). While not completely dismissing lectures (albeit in modified form), Barnett argues that teaching for supercomplexity requires that students must not simply observe multiple frameworks and uncertainty played out before them, no matter how skilfully, but must be 'required to handle conflicting ideas and perspectives and uncertain situations' (2000a:160).

The challenge is to produce a set of experiences that in turn encourage the formation of human qualities able to engage effectively with multiple frameworks, contesting value systems and open-ended action situations. A curriculum for supercomplexity has to be an educational project at once embracing the domains of being, knowing and action; in other words, a project of ontology, epistemology and praxis. Otherwise, the resources for coping with and continuing to prosper under conditions of supercomplexity are likely to be lacking (Barnett 2000c:263).

Such an approach to pedagogic practice means some relinquishing of *control* (not authority) by the teacher and the creation of ‘the pedagogical space ... [in which the student may]... develop her own voice’ (2000a:259). This is not sitting back and establishing a free-for-all, but rather creating a space for the student to accept responsibility for her actions and responses. Barnett points out that this ceding of control by the lecturer is conditional. If the students do not use the control they have been given for the purposes of ‘sustaining a value-added contribution to the pedagogical situation’, then the lecturer has the duty to ‘withdraw the pedagogical space at any time’ (Barnett 2000a:161).

For education to play a meaningful role in enabling pharmaceutical care, it will have to support students in: ‘taking a stand on the culture of one's community’, and facilitate ‘both personal and social transformation’ (Packer & Goicoechea, 2000: 3). The acceptance of pharmaceutical care as a philosophy of pharmacy practice (noted above 5.2.3 & 5.2.4) rather than a ‘step-by-step’ method, requires an intentionally transformative approach to teaching and learning, in order to challenge the dominance of product-oriented pharmacy practice. If, as has been argued, reflexivity is a necessary part of professionalism in an age of supercomplexity, and more fundamentally a necessary part of human agency, then pharmacy curricula must intentionally seek to harness and develop reflexive competence in pharmacy students, in relation to their practice. Reflexivity, however, is not purely a cognitive exercise, but involves the internal commentary emergent from our relations with the world, including the social world: that is, reflexivity involves a review of our emotions (Archer 2000:195; 7.3 below). However, the pharmacy curriculum, with its emphasis on cognitive and performative skills, has no place for deliberate attention to a reflexive consideration of these ‘commentaries on our concerns’ (Archer 2000:195; below 7.3.1).

I argue therefore that the idea of the ‘reflective practitioner’ proposed by Droege (2003 following Schön), should be extended to the idea of a *reflexive* practitioner – a concept in line with the understandings of both *professional* and *pharmaceutical care* which have been considered above. Education for professional pharmacy practice based on pharmaceutical care, requires the development of *meta-* or *reflexive competence*, which must integrate the *practical* or *instrumental-procedural knowing*, and *foundational* or *substantive-theoretical knowing*, that have dominated professional education in the past. Pharmacy practice requires the integration of the latter two competences and the

application of the resultant ‘knowing’ to and in the non-linear world of human illness. It requires therefore the ability to think critically:

...the ability to assess both explicit and implicit claims, so as to determine what I ought to do, or which claim I ought to accept, on the basis of good reasons for that decision – rather than on the basis of force, chance or custom (Langsdorf 1988 in Mezirow & Associates 1990: xvii).

Further than this – which as it stands simply suggests analysis and evaluation – is the awareness and ability to ask ‘what’s happening here?’: in whose interests are assertions made; what assumptions / presumptions are being made; who is being silenced here, and why? Within the context of pharmacy this could translate into questions about appropriateness of therapeutic alternatives, both pharmaceutically and ethically, and about the patient’s rights and needs. Such an understanding of thinking demands *meta-* or *reflexive competence*, and is congruent with critical realism (*judgemental rationalism* – Bhaskar 2002; *reflexivity* – Archer 2000; 2002; 2003); *understanding* in the sociocultural epistemological position articulated by Wells (1999); and supports the understanding of professionalism proposed by Evetts (2003). It also emphasises the critical dimension of the covenantal relationship of and in pharmaceutical care.

Fundamental to the competence required for professional pharmaceutical care based on a covenantal relationship, is the pharmacist’s ability to understand (*verstehen*– Schwandt 1999 and see above 4.1.2), and value the patient’s perspective. This is profoundly difficult if the emphasis of the pharmacist’s education has been on *practical* or *instrumental-procedural knowing* and *foundational* or *substantive-theoretical knowing*, which has little place for lay knowledge (so clearly illustrated in Prior 2003). The practical question for pharmacy educators is, how is it possible within the crowded curriculum of a pharmacy degree, to create space to develop affective competence (*aesthetic-Meta knowing* 3.1.2 above), while not compromising the already pressured cognitive competence currently valued?

As noted in the introductory chapter (1.2) the teaching and learning response I propose arises from my own embodied experience as a patient, and as an academic development consultant working with the Pharmacy Faculty at Rhodes University, followed by conversations with second year students taking Pharmacy Administration & Practice 1 during 2001. The experiences (or roles) of patient and educator were linked theoretically by Barnett’s ‘supercomplexity’. The pedagogic approach proposed below developed from

an initial reflection on my experiences as an educator, whose teaching practice has been informed by a sociocultural epistemology. Added to this were two concepts derived from within the literature that informs higher education academic development and the support of non-traditional students in their access to university education: the concept of ‘discourse’ (3.1.4 above), and Morrow’s (1993) usage of *epistemological access*.

7.2.3 *Epistemological access?*

Kress’s understanding of discourse was noted above (3.1.4), but it bears repeating here because, I argue, it helps to illumine an understanding of *epistemological access*.

According to Kress:

A discourse provides a set of possible statements about a given area and organises and gives structure to that manner in which a particular topic, object, process is to be talked about. In that it provides descriptions, rules, permissions and prohibitions of social and individual actions (Kress 1989:7).

The link between discourse and the sociocultural epistemology which informs this study has already been noted (3.1.3 & 3.1.4 above). The concept of *epistemological access* derives from philosophy, but appears to have first surfaced in the discourse community of higher education academic development in the context of supporting non-traditional students ‘access and success’ to and in, higher education in South Africa (Morrow 1993). Although Morrow has been frequently cited, his usage of the term remains tantalizingly opaque. In a paper addressing an aspect of values and schooling in post-Apartheid South Africa, South African educationalist Jonathan Jansen (with no reference to Morrow) unpacks the term as follows: ‘It is one thing to allow children access through the gates of a school i.e., physical access. It is quite another thing to allow young people *access to knowledge - its various forms, how it is organised, its value bases, its politics, and its power*. In other words, epistemological access’ [*sic*] (Jansen 2001: HTML document – italics added). Such an understanding certainly accords with Morrow’s apparent usage, and the usage to which the term is put in academic development literature: ‘the crucial issue is not of granting formal access to the institution, but rather of granting epistemological access to the processes of knowledge construction which sustain it’ (Boughiey 2002:305). Raising awareness of discourse, provides one way of making people aware of the explicit and implicit rules, values and assumptions which are at work within different communities’ ways of knowing.

Following Schwandt (1999), and Kress (1989 & above 3.1.4), and in the context of pharmacy students trying to come to grips with issues of medicine-taking behaviour related to chronic illness, epistemological access would mean giving students a way to:

describe and delimit what it is possible to say (and by extension – what is possible to do or not to do) with respect to instantiations of particular roles by people living with chronic illness.

This would include access to, and recognition of, the knowledge held by patients themselves; knowledge that will impact on their decisions as patient-agents with respect to therapeutic choices. This is the ‘*knowledge of illness — its various forms, how it is organised, its value bases, its politics, and its power*’ (Jansen 2001, above), as distinct from but not denying, knowledge of disease (4.3.2, above). This recognition of a patient’s knowledge is also congruent with the critical/social realist understanding of a social actor as one who personifies the social role which s/he chooses to occupy (as distinct from the agency they exercise within the social collective they inherit) (Archer 1995).

Pharmacy students would need, however, to gain epistemological access to the discourse of chronic illness in such a way that they are able to think critically (above 6.2) about the discourse in which their understanding of themselves as pharmacy professionals is framed, and the way that professional discourse has framed the ‘patient’, ‘chronic illness’ and ‘medicine-taking behaviour’. Because pharmaceutical care requires a professional covenantal relationship, by simply seeking to gain an understanding of chronic illness without the reflexive consideration of their own practice (including discipline knowledge), students would fail to recognise the assumptions they bring to the ‘act of pharmacy’, and fail to understand how the structural influences of pharmacy may enable / constrain both their agency and the agency of the patient. An understanding of epistemological access that explicitly includes reflexivity, could support Droege’s call for teaching and learning practice that will ‘help to build a new conceptual framework of ... professional practice’ (Droege 2003:72).

7.3 Coming to know - experience and learning

[The] sociocultural [perspective on learning] emphasizes characteristics of social participation, relationships (such as that between novice and expert, newcomer and old timer), the setting of activity, and historical change (Packer & Goicoechea, 2000: 2).

Central to Wells’s model of sociocultural epistemology is his discussion of the ‘ontological status’ of knowledge, which he argues lies in the object of the activity of knowing (3.1.3). As noted, Wells offered the following understanding of knowing as:

...the intentional activity of individuals who, as members of a community, make use of and produce representations in the collaborative attempt to better understand and transform their shared world (1999:76. Italics in original).

This conception of knowing brings together *understanding* (Schwandt 1999) and *transforming* (Archer 1995; 2000; 2002; 2003; Packer & Goicoechea, 2000; Droege 2003). As noted above, Wells goes beyond describing ‘knowing’, and proposes his ‘Spiral of Knowing’ (Figure 3-2, 3.1.3 above) as a model of how we *come to know*. While the image of a ‘spiral’ militates against suggesting a simple ‘destination’, Wells nonetheless offers a model which begins in experience, engages with information, undertakes knowledge-building with others to reach understanding, represented by fullest expansion of the spiral, and from which the process begins again. At each ‘end’ of the spiral lies personal meaning (experience and understanding, respectively), while the movement from one to the other is mediated by social engagement (with information and knowledge building – 3.1.3, above). All this, of course, while the ‘spiral’ is moving through time along the ‘modes of knowing’ axis from Instrumental to Theoretical (Figure 3-2, 3.1.3, above).

It is in the mediation of personal experience and understanding through social engagement, that connections with Archer’s understanding of reflexivity appear (above 2.3.4; Archer 2003). Wells makes no mention of reflexivity associated with knowing, but he does refer to ‘meta-knowing’ as a mode of knowing by individuals seeking to understand and control their own mental activities (Wells 1999 and Table 3-i, 3.1.2, above). This understanding bears a close resemblance to reflexivity as the practice ‘of the *internal dialogue* through and in which we go about formulating a thought, questioning ourselves, clarifying our beliefs and inclinations, diagnosing our situations, deliberating about our concerns and defining our own projects’ (2.3.4 above; Archer 2003:103). Arguing that a sociocultural approach to pedagogy is appropriate for supercomplexity, Edwards reflects that the concept of the mind held in current sociocultural theory ‘is socially formed, but it is an active outward-looking mind and not merely socially determined’ (Edwards 2001:170). Sociocultural understandings of learning thus emphasise the kind of agency rooted in reflexivity for which Archer (2000;2002;2003) argues: ‘In this model of learning we are therefore concerned with learners’ agency and intentional actions, opportunities for their active engagement, an understanding of their previous learning, and both the affective and intellectual features of those experiences’ (Edwards 2001:171).

To be consistent with such an epistemological perspective, any pedagogic practice must thus enable students to: explore their own experience; access information; engage in knowledge building through social engagement; and articulate their understanding. In addition it must seek to ‘produce a set of experiences that ... encourage the formation of human qualities able to engage effectively with multiple frameworks, contesting value systems and open-ended action situations’ (Barnett 2000c:263 – above 6.2.2).

The ‘model’ of pedagogic practice that suggests itself (especially in terms of professional education) is *experiential learning* (Kolb 1984; Miller & Boud 1996; Jarvis, Holford & Griffin 2003), also known as *active learning* (Hovelynck 2002). The distinguishing feature of experiential learning as a pedagogic practice is ‘when educators deliberately plan learning in which the learners have a primary experience of the external world’ (Jarvis *et al.* 2003:67). However, both the term ‘experiential learning’ and some of its applications are problematic. Many examples suggest a lack of theoretical engagement and rigour, and result in little more than ‘experiences / activities’ coupled with superficial reflection at the level of performance (Hovelynck 2002; Jarvis *et al.* 2003). The existence of such examples, however, does not exhaust experiential / active learning.

Despite the tendency in higher education circles to see experiential learning as un-/under theorised, it has solid theoretical roots in the work of Jean Piaget, John Dewey, and Kurt Lewin (Kolb 1984:15). By the 1970s experiential learning was being seen as a way of responding to what Barnett would later call supercomplexity, what Chickering termed ‘the major social problems rushing toward us’ (Chickering 1977 in Kolb 1984: 7 – 8). Kolb (1984: 26 – 38) argues that, rooted in the theories of Piaget, Dewey, Lewin, Bruner and Freire, experiential learning can be understood as:

- **A continuous process grounded in experience** [based on our continuous consciousness as human beings, a matter central to Archer’s understanding of personal identity – Archer 2000; 2002; 2003]. This denies the idea of a student being a *tabula rasa*, and reminds us that we have to help students make explicit and examine the disjunction between, their *theories in use* and their *espoused theories* (Argyris and Schön 1974 in Kolb 1984: 29);
- **The process of learning requires the resolution of conflicts between opposing ways of dealing with the world** [which accords with Barnett’s challenge for teaching and learning for supercomplexity (Barnett 2000a, b, c). Quite explicitly

Kolb argues that experiential learning includes reflection, abstract conceptualization, and active experimentation (1984:30 – 31). These are essentially the elements of reflexivity. This understanding reflects the role of emotions in personal identity formation proposed by Archer (2000 – and see below 6.3.1);

- **Learning is a holistic process;** ‘it involves the integrated functioning of the total organism – thinking, feeling, perceiving and behaving’ (Kolb 1984:31) [congruent with Archer (1985; 2000; 2003), Wells (1999) and Barnett (2000a, b, c.)];
- **Learning involves transactions between the person and the environment;** ‘This learning is a social process; and thus, the course of individual development is shaped by the cultural system of social knowledge’ (Kolb 1984:133). This too is congruent with Archer’s description of agency and structure, reflecting social constraints/enablers, reproduction/elaboration (Archer 1985; 2000; 2003). It is also congruent with Sayer’s emphasis on ‘knowledge... [as]... primarily gained through activity both in attempting to change our environment (through labour or work) and through interaction with other people, using shared resources, in particular a common language’ (Sayer 1992:13 – 14);
- **Learning is the process of creating knowledge;** knowledge results from transaction between personal and social. This reflects Well’s spiral of knowing (1999), Sayer’s critical realist understanding of knowing (1992), and Archer’s understanding of reflexivity.

Particular concerns regarding experiential learning include that students miss the learning opportunity because of prior assumptions that the world is predictable and unchanging, and that current knowledge is sufficient. At the other extreme is that students are so threatened by the learning experience, that change is consciously rejected. This latter does not mean that no learning occurs, as a student may learn that they cannot engage in the type of activity, and so may learn something about themselves (Jarvis *et al.* 2003). A further caveat with regard to experiential learning, is the acknowledgement that learning and / or change will not necessarily occur in a given ‘episode’ of experience *qua* experience (Jarvis, *et al.* 2003).

Where learning does not occur, or where learning remains at the level of ‘socially reproductive’ learning (e.g. memorization or rote learning and skills learning), what is missing is reflective learning (Jarvis *et al.* 2003:63). The form of learning that is most

effective for professionals (given the need to deal with supercomplexity) is ‘active reflection... [which] ...involves not only learning a skill but also the concepts that underpin the practice....Additionally, this form of learning is also accompanied by other forms of learning involving attitudes, emotions and so on’ (Jarvis *et al.* 2003:64). Kolb (1984), Yorks and Kasl (2002), and Jarvis *et al.* (2003) stress the significance of an affective element in experiential learning, and this is especially so when reflective learning is present. Learning is thus understood as ‘a complex process, involving internal and socially constructed processes mediated by affect and motivation’ (McAlpine 2004:119).

7.3.1 Affective Learning

So what, specifically, has affective learning to do with competence for pharmaceutical care? Archer provides a fundamental link between emotions (as ‘commentaries on human concerns’, and therefore fundamental to reflexivity), and ‘care’, noting that emotions are ‘central to things we care about and to the act of caring itself’ (2000:194). The imperative for affective learning rests in the need to place values firmly on the pharmacy agenda. Four references suffice to illustrate the professional motivation. In 1998 Knowlton argued that pharmacy was facing ‘turbulent times’. Externally it was being threatened by managed health care, and internally by the urgent need to undergo a shift from drug-centred practice, to the ‘patient-centred’ practice of pharmaceutical care (Knowlton 1998:1477). What was needed to help pharmacy survive the ‘turbulent times’ was to consider, among other things, ‘what our moral capital root-structure is for weathering the elements – or what opportunities this change promotes vis-à-vis ethical dialogue’ (Knowlton 1998:1477). This position is supported by Latif, the primary researcher in the field of moral reasoning and pharmacy (Wingfield, Bissell & Anderson 2004), who argues that: ‘When tasks are non-standardized and ill-defined, as is often the case in the provision of pharmaceutical care, individuals at higher levels of moral reasoning may have better conceptual tools for handling an ethical or social dilemma’ (Latif 2003:2). Wingfield, Bissell and Anderson, in one of their conclusions in a 2004 survey of literature on pharmacy ethics, suggest: ‘More effort could perhaps be made by pharmacy practice researchers to be alert to and aware of the ethical issues surrounding their work, and for them to consider the educational potential of their findings in raising such awareness amongst present and future pharmacy practitioners’. They call for further research in educational initiatives to develop ‘ethical competence’ prior to entering practice (2004:2392; 2383). In an article examining models of pharmacy practice that seek to inform ‘Total Pharmacy Practice,’ Nimmo and Holland note:

According to the American Association of College of Pharmacy Task Force on Professional Socialization, “the future of pharmacy not only rests on the technical expertise of pharmacists, but also on their affective approach to practice.” (Nimmo & Holland 1999:1986).

More recently, illustrating something of the problem of professional values in pharmacy in South Africa, the South African Pharmacy Council expressed serious concern about growing violations of professional codes of practice among South African pharmacists. Asking whether South African pharmacists are ‘acting as professionals or are they shopkeepers/dealers in medicine similar to the shoe-shop owner or grocer?’, the editor of the Council’s publication reminded pharmacists of the Council’s commitment to pharmaceutical care and professional ethics. Listing a number of recent violations of professional ethics, Masongo cautions ‘if pharmacists behave in the way as described [sic]...they cannot be regarded as custodians of medicines and will not be regarded as professionals’ (Masongo 2005).

Pharmacy is not alone in urgent calls for the ‘reskilling’ of its professionals. In an examination of medical curricula in the light of growing ‘dissonance between the desired and perceived outcomes of medical education’, Howe (2002:354) argues that:

The literature suggests that successful professional development needs to be based on explicit values, which are repeatedly demonstrated in the learning environment, and modelled by senior colleagues and tutors; that the curriculum should incorporate a clear model of emotional as well as cognitive development... (Howe 2002:353).

Referring to Kolb, Schön and Boud, Howe argues for a curriculum model based on the approach outlined above. Howe recognises the sociological concern that dominant positivist approaches to medical education will seek to nullify, openly or covertly, any attempts by affective learning to gain access to the medical curriculum (Howe 2002). From within radiological education, Van Valkenburg and Holden argue that students in healthcare education ‘develop an attitude of affective neutrality...attributed to their socialization during educational programmes’, and that the failure to address the affective domain ‘results in undesirable behaviour patterns that negatively influence the quality of care patients receive...’ (2004:347). Borrell-Carrió *et al.* also argue for the need for ‘emotional education’, in medical education, not simply to support a relationship-centred approach to healthcare, but to support clinical decision-making through ‘tolerance of uncertainty’ (2004:580).

In nursing education (acknowledged by Howe to be much more ‘explicit about the development of attitudes’ – Howe 2002:354), O’Connor, Hyde and Treacy argue that reflective practice and ‘reflective learning through the affective domain’ are crucial within nursing education with its emphasis on care (2003:107). Medical and nursing conceptions of care are significant for educational initiatives concerning pharmaceutical care, not merely in the general sense of relating ‘care’, but specifically because in Hepler’s original proposal of pharmaceutical care, it was to the concepts of medical care and nursing care that he turned for analogy (Hepler 1987:376).

Kolb *et al.* note that teaching in the affective domain has been generally undervalued in Western education, because in the ‘democratic traditions of the Western world’ the affective domain is regarded as private. This is so entrenched that permitting the (explicit) entrance of affective teaching into education, is regarded as indoctrination (1984:18). Affective learning is also hard to assess (measure?) and takes time to develop. The first concern is rooted in positivist assumptions that facts are value free, and cognitive education therefore was (and is) value neutral; something which social science has largely rejected, and critical realist ontological commitments certainly rebuff (Bhaskar 1978; 1979; 2002). Values, as Kress (1989) and Gee (1990) argue, are implicit – and explicit – in discourse. To that extent, affective education is ever present – what differs is both the intentionality and the reflexivity involved.

Understanding of affective learning often centres on feelings to the exclusion of values and attitudes, which is problematic when considered in relation to developing reflexivity (O’Connor *et al.* 2003). This may well have arisen in reaction to the over-emphasis of behaviourist and/or cognitive approaches to teaching, which have pervaded in healthcare settings for so long; something that accords with the way positivist Modernity’s Man ‘sought to take the passion out of his or her preferences’ (Archer 2000:194). Conventionally approaches to affective learning have been based on Krathwohl, Bloom and Masia’s (1964) taxonomy of educational objectives for the affective domain (O’Connor *et al.* 2003; Graham 2003 – See Appendix ‘C’). O’Connor *et al.* note recent trends toward the use of models proposed by Gibbs, and Boud, Keogh, and Walker (Boud, Keogh, and Walker 1985 and Gibbs 1988 in O’Connor *et al.* 2003:117). Graham (2003) proposes the further example of Martin and Reigeluth’s expanded affective taxonomy. In this taxonomy the affective domain is expanded to include emotional, moral, social,

spiritual, aesthetic and motivational dimensions (Martin & Reigeluth 1999 in Graham 2003).

While Krathwhol *et al.*'s seminal work has been extended, the more recent versions do not appear to add substantially to the usefulness of the original. That said the behaviourist theoretical underpinning in Krathwohl *et al.* needs challenging by more recent insight. I have chosen to use Archer's understanding of emotion as part of human agency, to support the affective learning in the pedagogic practice I will propose. Archer (2000) offers a nuanced and rich understanding, well integrated into social realist theory, congruent with the ontological and epistemological perspectives underpinning this study, and which supports the concept of supercomplexity I have argued is appropriate for both professional (pharmacy) education and understanding chronic illness.

In Archer's critical/social realist understanding of human agency, emotions are crucial to the formation of our personal identity, and to our interaction with the social order that forms our social identity. Quoting Jon Elster, Archer affirms '... "simply, emotions matter because if we did not have them nothing else would matter.... Emotions are the stuff of life"...' (Elster 1999 in Archer 2000:194). Emotions are central to the internal conversation from which our personal identity emerges (Archer 2000; 2002; 2003), and are present as 'commentaries on our concerns' (Archer 2000:195). The commentaries, however, go beyond simply being statements of how we feel about something. They signal the significance of a situation in relation to our ultimate concerns, and act as 'affective modes of awareness' (Charles Taylor 1985 in Archer 2000:195). Emotions relate to something in the world; they are emergent from the relationship between an event's significance and our interests. Where an event is interpreted as having no significance for our concerns, no emotional commentary emerges. (A passing bus is barely noticed, unless it happens to be the bus we intended to catch to our job interview, and either we are late or it was early, and its passing suggests we may or have already missed it).

Emotions then

- '...are emergent from our human relationships with the natural, practical and discursive orders of reality respectively...', but
- we can reflexively re-evaluate such commentaries, and we can make them known and even change them through the on-going internal conversation

- ‘...which is a ceaseless [private, personal] discussion about the satisfaction of our ultimate concerns and a monitoring of the self and its commitments in relation to commentaries received...’ (Archer 2000:195).

An important element of emotion and our internal conversations, is that the latter are essentially about the relationship between the way we know the world and the way it is: ‘between our ontology and our epistemology’. Thus emotions as commentary on our concerns, are not flights of fancy: ‘we are not free to make what we will of a state of affairs, independently of how things are’ (unless, of course, pathologically) (Archer 2000:196).

Archer cautions against an incipient nominalism which wants then to ‘list’ emotions. This is problematic because such a list is both language and culture dependant, and we may fall into the fallacy of acting on the assumption that because a linguistic label does not appear to exist in a particular culture, there is ‘a corresponding absence of feeling’ (2000:197). Archer’s concern is echoed by Chambon and Irving, seeking to develop an ethics and knowledge of care:

How do we engage with complex human experiences in health, illness, and in daily living when faced with a troublesome and/or unknown set of circumstances? How do we engage with our own and another person’s turmoil? Professionals who have developed a language of emotions to try to communicate about these situations have often reduced the task to an impoverished vocabulary of discrete moods—sadness, anger, joy, or relief. These ways of eliciting and registering moods remove us from complicated experiences (Foote & Frank, 1999). They place us at a distance, in a position of aboutness from the experiences of others (2003:268).

Instead of a tick-list of ‘emotions’, Archer proposes three ‘emotional clusters’ related to the orders of reality – natural, practical and discursive (2000:197). These clusters, their concerns and imports (significance), are summarised in Table 7-iii.

OBJECT OF EMOTIONS	CONCERNS	IMPORTS (significance)	EMERGENCE FROM
Natural order	Physical well-being	visceral	Body-environment relations
Practical order	Performative achievement	competence	Subject/object relations
Discursive order	Self-worth	normative	Subject/subject relations

Table 7-iii: The emergence of (first order) emotions (adapted from Archer 2000:199)

In the *natural order* cluster, emotions ensure that we are aware of the significance of the environment for us at an instinctive (visceral) level. We may, at a second order level, revise that significance (a vicious-looking dog may suddenly appear on the path between our gate and our house – but we recognize it as our dog, and its rush towards us is re-

interpreted from ‘attack, danger’, to ‘hearty welcome’). What gives emotion significance at this level, is that emotion is rooted in consciousness of ourselves being the same being over time: ‘Anticipation is the key to affect’ (Archer 2000:202). This means that emotions related to the natural order do have a cognitive element: our emotions call upon our past experiences in order to anticipate a future consequence. The cognitive element – built into anticipation – means that emotional commentaries are ‘corrigible’ (Archer 2000:202).

In the *practical order*, our concerns form the subject’s (our) judgement about our action on an object, and are emergent from the relationship between ourselves and the task we are faced with, or have undertaken. Here again, the cognitive element affirms corrigibility (we can be wrong about our skill as a trumpet player), but here the judgement is the *subject’s* judgement on the subject’s performance, rather than social judgement on our performance. If the subject has low or no concern to achieve well in a task, then social disapproval will have little influence on their actions. Equally, social approbation is minimised in its effect (Archer 2000). Part of the emotional commentary in this order amounts to a cost-benefit analysis, because we decide here how much cost we are prepared to endure in order to achieve a skill or competence.

Emotions emergent within this subject-object cluster have specific relevance for education: ‘If we consistently fall short on a particular task, meaning that we cannot match up to objective standards of performance achievement, then frustration, boredom and depression [may] ensue as emotional commentary....The same is the case for tasks which are insufficiently demanding’ (Archer 2000:212). Note that this is based on *our* (subject) judgement of what an ‘objective standard’ is, not the social judgement of others, although such judgement does provide emotional commentary in another cluster (see below). Clearly this has connections in working life as well, allied to Marx’s ‘alienation’: where we are involved in a monotonous daily task, which in no way relates to our concerns (except perhaps to afford some financial benefit). Our self-monitoring in the practical realm helps us become aware of what is important to us, of the meaning and importance of self-sacrifice (including the reduction of the force of social criticism – at the discursive level – and of readiness to endure present pain for future pleasure – at the natural level) (Archer 2000). Further implications for education lie in the links between knowledge and emotions associated with the practical order (Table 7-iv):

Knowledge	Emotions
Performative – so a ‘feel for’ (as opposed to declarative)	Performative – a ‘feeling for’ which like the knowledge is independent of language
Implicit – ‘encoded through bodily skills’	Implicit – sensing competence or incompetence
Tacit – known through activity	Tacit – known through activity (including that of appreciative spectator)
Extensive of bodily powers	Extends our emotional repertoire and extends to include commentary for self-as-spectator / observer through appreciation for performance

Table 7-iv: Knowledge / emotion connections in the practical order of reality (Archer 2000:213 - 4)

In the *social order*, emotions are emergent from subject/subject relationships. However, as society cannot simply be reduced to the individual people in it, the relationships upon which emotional commentary is made, include ‘society’s normative order’ (Archer 2000:215). As suggested above, the standards for emotions in this order relate to society’s approbation or disapproval. Emotions in the social order relate to society’s moral order, and are thus:

socially *constituted* properties which are emergent from the internal relations between the subject’s concerns and society’s normativity. Their emergence is thus dependent upon three factors: our subject status in society, the receipt of moral evaluations from the social order, and the conjunction between our personal concerns and the nature of society’s norms (Archer 2000:215 Italics in original).

Clearly there are significant differences between the emotions emergent from relations between body/environment and subject/object. In these orders, respectively,

- something is either a threat or not a threat (and just because we view a mouse as threatening does not – objectively – make it so), or
- we have sufficient mastery of a skill or we do not (we can ride an appropriate, fully functional bicycle, or we cannot).

In the *moral order* this is less clear. What is shameful in one society is not in another. Witness for example the strong reactions of Victorian era missionaries to African dress codes. Here something shameful in Victorian England was acceptable in societies in the southern tip of Africa. As Archer notes: ‘shame has no efficacy without the subject’s concordance’ (2000:216). One of the drivers of structural elaboration rests in the way agents receive and either accept (morphostasis) social conventions, or elaborate / transform them, in part through their rejection of them (morphogenesis). ‘[W]hat makes this normative discourse [of social conventions / mores] apply to us?’ asks Archer (2000:218). At one level, this is learned ‘like chemistry’ (Archer 2000:218), but this can lead to outward compliance with no emotional ‘concern’ (students can attend a lecture without any

attempt at becoming social actors, involved in their own learning). It is, in other words, only our own clarity about what matters to us as persons that authorizes the emotional commentary in the social order, and ‘...determines which normative evaluations matter enough for us to be emotional about them’ (Archer 2000:219). While the distinction may be subtle in extreme cases (one may act to comply with social norms out of fear of physical punishment/pain – a natural order emotion), this does not mean that we have any social order emotional commitment to the norm.

As Archer notes, this understanding presents humans with a problem – each person has to deal with three ‘emotional commentaries on their concerns’, commentaries which do not necessarily fit together at any time. Frequently giving one commentary preference compromises another, and yet because we have to live in all three orders (natural, practical and social), we have to find a way of living that achieves a satisfactory balance. The ‘precise balance we strike between our concerns, and what precisely figures amongst an individual’s concerns is what gives us our strict identity as *particular persons*’ (Archer 2000:221 *Italics in original*). It is this need to reach an individual balance, that places reflexivity so central to human identity, agency, and our being social actors (not merely occupying a social role – as pharmacist – but imbuing that role with our personality – Archer 1995; 2000).

Given this understanding of emotions (inextricably tied to moral action, values and attitudes), affective learning in this context involves becoming reflexively aware of our inner dialogue, as it relates to our occupation, as social actors, in the role of pharmacist. It must also involve exposure to situations which facilitate the examining of the relationships between ourselves and the environment, our subject/object relations (our mastery of skills), and our subject/ subject relations (our values, attitudes and social concerns).

Affective competence thus includes self-knowledge, social, and cultural knowledge specifically with respect to moral and ethical values. Pharmacy students should be expected to develop critical stances toward ‘given’ understandings, and to develop skills to negotiate their own, informed, commitments with respect to each of the orders of social reality. This is especially so when working within the supercomplex contexts of chronic illness (such as HIV/AIDS), which at times will raise concerns for the pharmacist in all three orders: natural, practical and social.

I have argued that epistemological access to chronic illness requires understanding discourse, and developing a reflexivity which demands affective competence. For this I propose that a pedagogic practice based on experiential / active learning, offers a holistic pedagogic model for learning involving all three orders of reality (natural, practical and discursive). Such a pedagogic model is aligned with the critical/social realist understanding of the primacy of practice, and the assertion that:

the embodied practices of human beings in the world [are] more important than their social relations for the emergence of selfhood, meaning a continuous sense of self, and for the development of its properties and powers, meaning reflexivity....[This] is also a question of viewing language itself as a practical activity, which means taking seriously that our words are quite literally deeds, and ones which do not enjoy hegemony over our other doings in the emergence of our sense of self (Archer 2000:121).

It is to a brief theoretical consideration of ways in which experiential learning could be facilitated within the real-world constraints of the Bachelor of Pharmacy curriculum, at Rhodes University, that I now turn.

7.3.2 *Creating epistemological and ontological disturbance*

The most effective learning will occur when learners use knowledge to perform meaningful tasks. For example, students might initially learn about the pharmacological properties of a drug by attending classes in a college of pharmacy. Students really learn about them, however, only after they have worked with a patient taking this drug: Trying to decide what dosage works best or how to resolve a drug therapy problem related to this drug in the context of real world constraints (Droege 2003:71).

Recalling Hepler's understanding of the covenantal relationship of pharmaceutical care (5.2.3), the 'offer' within the covenant is professional competence. Part of that competence is undoubtedly specialist knowledge offered through the science-based disciplines of pharmaceutical chemistry, pharmacology, and pharmaceuticals. That competence must be supplemented and complemented by the ability to exercise 'professional, social and communication skills, and exhibit specific attitudes and behaviour, to enable them effectively to discharge their professional roles' (FIP 2000:3). While these skills should be integrated throughout the curriculum, they remain the specific concern of courses similar to the Pharmacy Administration and Practice (PAP) course within the Faculty of Pharmacy at Rhodes University (Futter 1996; 2002a; 2002b).

A recurrent theme in the literature around medical and pharmaceutical education, is the stress on the need for student contact with ‘real life’ patients during their training, in order to enhance professional communication skills (Droege 2003; Das & Das 2002; Pereira & Murzyn 2001; Wykurz & Kelly 2002; Rees, Sheard & McPherson 2004). Since the 1970s a substantial field of practice and research has emerged around the use of narrative – primarily, but not exclusively, using patient’s illness narratives – to support the development of appropriate values and skills in working with patients (Hudson-Jones 1997; Greenhalgh & Hurwitz 1999; Miyasaka, Yamanouchi, Dewa, & Sakurai, 2000; Murray, McKay, Thompson, & Donald 2000). In each case the primary concern has been to grant healthcare professionals access to the patient’s experience. This is reflective of Barnett’s ‘supercomplexity’: confronting students with multiple, conflicting, interpretive frameworks. One group of medical students arguing for increased inclusion of what, in some examples of the literature is termed ‘medical humanities’, note:

Education is "what survives when what has been learned has been forgotten." Medical education should be much more than training for a job. Practical experience and knowledge of facts are not enough. An openness to lifelong learning, the ability to communicate and empathise with other people, and an understanding of the need for reflective practice are all important goals of the undergraduate curriculum. Although scientific understanding is an important part of these skills, exposure to the humanities can further these areas, which have often been neglected in the past. We believe that the skills that medical humanities courses can impart are invaluable for the development of the sort of doctors people want and our generation of medical students should be (Hodgson & Smart 1998).

Interaction with patients, then, must form one component of an approach to pharmacy education aimed at developing epistemological access to the patient’s experience: ‘... in order for pharmacists to apply their knowledge in the context of direct patient care, the curriculum will have to reflect exactly that, patient care, and allow students to interact with numerous patients to become reflective practitioners’ (Droege 2003:73).

However, simply creating curriculum space for interaction with patients is insufficient to ‘create epistemological and ontological disturbance in the minds and in the *being* of students: it has to pose cognitively and experientially the radical uncertainty presented by supercomplexity ... [chronic illness]. Students have to come to *feel* in every sense the utter insecurity of the post-modern world’ (Barnett 2000a:154). Without this sense, it is too easy to maintain the discourse of expertise vs. lay ignorance. Reflexivity requires a level of examination of assumptions, and an exposure to some of the implications of understanding

discourse, provides a way of critically examining assumptions. When we begin to realise that words are not innocent but ‘come bearing gifts’, often implicit, and unexamined, the experience is frequently unsettling. I propose that a place to begin in problematising the discourse of pharmacy, is with a concept central to the practitioner/patient interaction, and familiar to students.

The particular focus of much healthcare language relating to the practitioner/patient space revolves around the concept of *patient compliance* (see 5.1.2 above). The term remains in use in the Pharmaceutical Care Plan used (in 2004) by the Rhodes Faculty of Pharmacy (Appendix ‘B’), and alternates in course documentation between ‘compliance’ and ‘adherence’ (Futter 2002a:71). As noted above (5.1.3) ‘adherence’ was introduced with the intention of reducing the ‘attribution of greater power to the doctor in the doctor-patient relationship which the term compliance brings’ (Vermeire, *et al.*2001:332). In practice ‘adherence’ has become a synonym for ‘compliance’: patient obedience to the professional’s orders. I propose that by subjecting the discourse of *compliance / adherence* to sociological critique, using a critical form of discourse analysis (Chapter 8, below), it will be possible to challenge the biomedical framework of pharmacist/patient interaction which is implicit in the Pharmaceutical Care Plan, and in the assumptions of pharmacy students. Behind this proposal lies the recognition that the ‘[speaking]...doing-being-valuing-believing combinations’ (Gee 1990:142) that constitute the biomedical discourse community, are like any other discourse practice, largely unconscious. When these are brought to conscious awareness they cease to function unproblematically (Gee 1990). One way of challenging the discourse used by pharmacy students relating to medicine-taking in chronic illness, is to expose them to the discourse of illness. This may have an effect similar to that found in second-language learner’s sudden critical awareness of their own discourse assumptions once they have to work with a new language (Gee 1990).

A third element of pedagogic practice would focus directly on the affective domain. Talking about the sociological criticism of positivist-biomedicine, focused on disease entities and treatment regimens, *may* challenge the views of students through sheer force of argument. Achieving this within a 26 hour teaching intervention, spread over 13 weeks, presenting an absolutely diluted ‘plea for the patient’ amidst a welter of product-focussed disciplines, is going to be challenging. Collier argues that:

To develop insight in a form which influences one’s active professional judgment, the usual lecture courses are inadequate: the learning must

have an experiential and indeed an existential basis: it must be ‘felt in the bones’. The existential dimension required in the exploration and analysis of value issues will only be secured if students become personally involved in the study of the motivation and morality of human situations... (1993:287).

Collier goes on to argue that feature films can usefully support such ‘existential’ engagement, a position supported by Lieberman, who argues that:

The unique qualities recommending the use of film as a teaching tool include its immersive quality; its ability to induce vicarious experience; its relevancy and reliability; its ability to stimulate active learning [experiential learning] and critical thinking; and its capacities to expand experiential possibilities (2002: 32).

Bailey and Ledford suggest that ‘[r]etention is also stimulated by the viewer's emotional involvement. In the darkness of the theater, untethered [sic] by the possibility of being seen, feelings are less liable to be repressed.... an individual may find it is easier to become lost in the experience. Indeed as the sensory, emotional, and intellectual facets of a person are engaged, both attention and retention are prone to increase’ (1994:HTML document). Olivier, facing the challenge of teaching ancient philosophy in the South African context, contends that ‘there is no better way to demonstrate the value of [a discipline students do not expect to learn from] than through the practice of involving students in the process of discovering for themselves that the very cultural practices and artefacts that they value, point to (or cover up) a host of as yet unexamined and potentially exciting questions’ (2000:HTML document). While the use of film in teaching is hardly novel, the literature regarding the use of film (including video, DVD) in teaching and learning is surprisingly thin. What there is, however, argues strongly for its effectiveness in active/experiential learning, and exposure to affective learning (Lieberman 2002). The literature also cautions about the dangers of ‘indoctrination’ and lapsing into entertainment: film selection is crucial, and thoughtful preparation and reflection are needed to support learning (Collier 1993; Lieberman 2002; Mallinger & Rossi 2003; Buchanan & Huczynski 2004).

Careful planning on the part of the educator needs to take place to reduce the drawbacks of using film as a experiential learning medium (being simply entertainment; situations in which offence or emotional trauma may be caused) (Lieberman (2002; Champoux 1999; Downey, Jackson, Puig & Furman 2003). More positively, as with any curriculum event, it must be intentionally integrated into the curriculum. The film selected for the proposed

intervention was ‘Wit’, (starring Emma Thompson, Christopher Lloyd, Eileen Atkins, Audra McDonald, Jonathan M. Woodward and Harold Pinter – Nichols 1998), based on the play by Margaret Edson (1999) to which reference has already been made (4.3.3). Having been pre-disposed to using ‘Wit’ simply through my own private viewing of it, the film’s usefulness for the purpose of this course was strengthened by the discovery of the ‘WitFilm Project’ involving 32 medical schools in North America, and its use in the United Kingdom for professional development of general practitioners in palliative care (WitFilm 2002; University of Arizona, 2002; Waters 2003). The WitFilm Project (2002) suggested pre- and post- viewing sessions in which educators and students prepared for, and reflected on, the experience of the film, a principle supported by Lieberman (2002), Champoux (1999), and Downey, Jackson, Puig and Furman (2003).

The second challenge of Barnett’s curriculum for supercomplexity was ‘to enable students to live at ease with this perplexing and unsettling environment’. Once again, affective learning offers directions that are, unsurprisingly, linked to developing reflexivity. Two of these suggestions are the use of student journals and learning portfolios, using frequent and prompt feedback to the students (McMullen, Endacott, Morag, Jasper, Miller, Scholes, & Webb 2003; Valkenburg & Holden 2004). One useful way of facilitating both ease and privacy in journal-keeping with students unfamiliar with the process, and at the same time facilitating prompt feedback on journals while reducing logistical challenges, is through an on-line Learning Management System (LMS), such as Moodle® (used in this project).

The advantage of using an LMS is that students can access the course resources for further consideration, complete journal entries and contact the course facilitators, at times which are convenient to the students. The LMS also provides an effective way of facilitating communications between students, and students and lecturers, between contact sessions. Access to a student Journal on most LMSs is restricted to the lecturer and each individual student, thus permitting a high degree of confidentiality to enhance reflection. LMSs usually support a Forum restricted to the students registered for a particular course, and in addition the usual access to course resources and assignments. Since pharmacy students are familiar with the use of computers by fourth year, computer literacy should not pose a significant difficulty.

While portfolios can be used in an on-going process throughout the course, and the regular feedback from the lecturers facilitates reflexivity, this can be extremely time-demanding for the students. With this in mind I propose using portfolios only for summative assessment. This means that students must be made aware from the beginning of the course that the portfolios will require evidence of ‘thoughtful and informed reflection’ integrated into each portfolio. Students must also be given a clear indication of assessment criteria, and the type of evidence that would be required to support portfolio assessment (for example, see Appendix ‘D’). Regular feedback from the lecturer can be channelled through weekly Journal tasks, which should be a course requirement (See Appendix ‘I’ for an example). Guiding questions / comments should be provided to suggest, but not confine students to, areas for reflection. While journals and portfolios provide significant resources for supporting students to ‘live at ease’ with supercomplexity, group-based, interactive and collaborative engagement in the classroom becomes essential (Wells 1999; Fraser & Greenhalgh 2001). It is also important for the lecturer to create space for student engagement in more traditional lecture-style sessions, so that (as was noted above) control is shared.

The elements of a teaching and learning intervention aimed at supporting students’ epistemological access to the supercomplexity of chronic illness could consist, then, of the following elements:

- Structured experiences of working with real patients;
- Provision of structured spaces in the curriculum for reflexivity and support;
- Affective learning experiences (for example role play and film) that seek to involve the ‘whole’ student, not merely a cognitive exercise;
- Exposure to ways of problematizing the assumptions of students with regard to the conceptual frameworks through which ‘patients’, medicine-taking, and disease/illness are understood;
- Assessment which extends the student beyond recall-based learning.

The following chapter considers *an* example, which, because of the numbers involved can serve as an illustrative example only¹, of how such a curriculum intervention could

¹ This was a fourth year elective which was limited to twelve students because of the numbers of available patients. Of those twelve, only seven agreed to participate in the study, thus making their journal entries and interview material available. All six of the patients were willing to have their interview responses used in the research.

be structured. The example is placed in the context of the overall qualification in which it was provided. Excerpts from the course material, student assumptions and responses as recorded in on-line journals, reflections on student work with patients, and transcripts of patient interviews conducted by students, will serve to illustrate the way the curriculum intervention sought to develop cognitive and affective capability. Some excerpts from final portfolios will be considered to illustrate ways in which students appear to have gained epistemological access to chronic illness, and patient's medicine-taking decision making. Comments from the course evaluation are also included which reflect not only the positive aspects of the students' experience of the course, but also highlight some practical and theoretical concerns.

Chapter 8 ‘What do they *teach* you in pharmacy school?’ – Gaining access to the discourse of chronic illness

The theoretical knowledge [our patient] has of her disease put us to shame and we were able to gain so much from listening [*sic*] to her physical, but more importantly her emotional journey. I think it is important for health professionals to read between the lines. Even though our questions as pharmacists are very clinical, the way a person answers each question, the language they use, the look on their faces can tell us so much about what they have been through and where they are emotionally... (Student Respondent 2L. Excerpt from ‘Reflection statement’ in final Chronic Illness Elective portfolio).

*Seeing past happening,
Hearing between words,
Touching heart stories.*

(Judith Gouwens in Janesick 2000:392).

8.1 Introduction

I have argued that the educational imperative to support a shift in pharmacy from a business, product-oriented occupation, toward a patient-care focussed profession, lies in the development of pharmacists’ reflexivity with respect to their professional expertise in pharmaceutical care.

Learning how to use our emotional capacities is just as important as learning how to use our rational capacities. We must learn how to read what is in other people’s hearts as well as in their heads. Words tell us but half the truth – if that; inflection, body language, and facial expression tell the rest – often the crucial rest (Tong 1997:158).

While this will influence all interactions with patients, it is in the pharmaceutical care of persons living with chronic illness, that such a covenantal approach could be most marked, simply because of the nature and complexity of therapeutic regimens involved in chronic illness (Chewning & Sleath 1996; Wade, Knight, Brushin, Morgan, Carr, Stevens, Day, Wood, & Fogg, 2001; Norris, Glasgow, Engelgau, O’Connor, & McColloch 2003; Michie, Miles, & Weinman 2003). Such an approach appears useful in facilitating the development of concordance between pharmacist and patient, with respect to medicine-taking decisions.

The teaching and learning intervention (‘the course’), which I describe below was designed for use in a Fourth Year Elective of Rhodes University’s Bachelor of Pharmacy degree. The location of the course as a fourth year Elective was based in part on the assumption that by

the fourth year students should have sufficient understanding of the disorder experienced by the patients participating in the study, and of the drugs conventionally used in the treatment of the disorder (rheumatoid arthritis). The Elective ran parallel with the Fourth Year Community Experience Programme (CEP), in which students use the same Pharmaceutical Care Plan (PCP) process as that used in the study. In the CEP the patients are drawn from among state hospital patients, and the majority are English alternative language speakers. This means that the majority of students' interactions with CEP patients are mediated through interpreters. In contrast, all the patient-respondents in the study were self-identified as English first language speakers. While only three of these were private patients, all were under the medical care of the same private specialist physician. Students thus received exposure to patients from different socio-economic groups across the two courses. Students were also exposed to a slightly wider range of chronic disorders and treatment contexts, as the CEP focussed on asthma, diabetes, and hypertension, while this study focussed exclusively on patients diagnosed with rheumatoid arthritis as the primary condition. Although the combination of similar learning experiences made the effectiveness of the elective difficult to assess for the purposes of this study, it was hoped that the juxtaposition of the experiences could positively influence the students' learning experience.

While a range of medical conditions were considered for the study, rheumatoid arthritis (RA) was selected in part because the treatment regimen is complex (see Appendix 'E' for a brief description of this disorder). This provided the students with an excellent example of a chronic illness in which a high risk drug regimen is normally prescribed, but which patients experience very differently. In addition RA is a disorder that has relatively low levels of social stigma, thus reducing possible patient discomfort arising from interaction with young students. This decision was made in consultation with the staff of the Faculty of Pharmacy, and with a specialist physician whose practice is located in Grahamstown and who, while not being a rheumatologist, has a 'Special Interest' in RA.

Students for the course were self-selected as the faculty offers all students in fourth year an opportunity to decide which two of fourteen electives they wish to join. Each student is required to undertake two electives, or a research project (Rhodes University 2005). Students were made aware that the medicine-taking and chronic illness elective was part of a doctoral study. They were also told that there were only twelve positions on the elective (two students per patient). Twenty three students signed up for the Elective. In consultation

with the PAP staff, it was decided that a process of selection should be applied to reduce the numbers to twelve. Initially those who had signed up for another elective run on the same day as the chronic illness elective (Managed care), were asked to choose which they wanted to prioritise, thus reducing time-table clashes. Those signed up for a closely related elective (Counselling) were asked to consider selecting another alternative, which some did. Applicants were then required to write letters of motivation which had to be submitted by a deadline (some withdrew at this point). Final selection was made in consultation with PAP staff and based on consideration of the letters of motivation. Places were offered to students who indicated preference for practice in community / retail or hospital pharmacy, rather than research or manufacturing, and who provided a considered reason for selecting the elective (as opposed to 'it looked interesting' type responses). The final twelve students selected for the course presented a fair reflection of the demographics of the country, with the exception that there were no White male students who submitted letters of application.

The time-tabling of the course was pre-determined by the Faculty and the University administration, and established as two 45-minute contact sessions per week for the thirteen teaching weeks of the First Semester. As the electives are set at 7.5 credit points (Appendix 'D' 1.2 - based on ten Notional Hours per credit point) this meant that the course was confined to 75 hours total teaching and learning time over thirteen weeks. This had to include contact hours, independent study / reading, assignments and summative assessment (See Appendix 'D', Course Outline). The course was facilitated by myself, with guest lectures from the Pharmacy Faculty (pharmacotherapy for RA), the specialist physician who assisted in identifying patients (pathogenesis, diagnosis and medical treatment of RA), and a lecturer from the Education Faculty (English and Film Studies), who assisted in the post-viewing reflection of the film (*Wit* – Nichols 1998). The Pharmacy Faculty pharmaceuticals professor who teaches the Therapeutic Drug Monitoring component in PAP, attended all sessions of the course, to act as an advisor on content relating directly to pharmaceutical therapy.

During the initial contact session the students taking the elective were given the option of becoming part of this illustrative study. Seven of the twelve students volunteered to join the study, and signed the consent forms required by the University Ethics Committee (S.1. in Appendix 'F'). Participating students agreed to all Journal entries, course assessment and related documentations, and transcripts of their interviews with patients being used in the

study, provided that their identities were kept confidential. Students were reminded of the professional requirement of confidentiality, and that no discussions of interview material were to take place in any way that compromised the rights and confidentiality of the patients. Students were cautioned that they were not to discuss patient interviews with anyone other than their interview partners or the course staff.

Patient selection was made through a local specialist physician who offered to support the study. The physician approached her patients and asked for an indication of interest in participating in the study. All patients were informed of the purpose of the study, the nature of the questions that may be posed, and their right to withdraw at any stage. Those patients who volunteered to participate in the study were informed in detail of the purpose of the study, and given the opportunity to discuss their participation with the specialist physician. All patients who agreed to take part in the study voluntarily signed the consent forms (P.1. in Appendix 'F'). All participating patients agreed to the interviews conducted by the pharmacy students being tape-recorded, and that transcripts could be used in research arising from the study, provided that their identities were kept confidential. Although patients and students were given the right and opportunity to review and comment on the transcripts, none chose to do so. Prior to the interviews taking place patients and students agreed that should concerns about the patient's wellbeing arise during, or as a result of the interview, the students, through me, could contact the specialist physician to inform her. In practice this did not arise.

The details of the course outlined below, and the subsequent discussion, serve to illustrate one way of using the curriculum elements noted above (6.3.2) to help pharmacy students gain epistemological access to medicine-taking decisions made by people living with chronic illness.

8.1.1 Outline of the course

The course was presented as outlined in Table (8.i) below. This provides simply an illustrative example of one way of in which a course could be structured according to the principles outlined in the previous chapter. The course began with a consideration of student and facilitator expectations, during which students identified questions or areas of interest they wanted to consider during the course, and these were then linked to the various sections or sessions in the course.

In order to prepare students for their interviews with patients, the first sessions were aimed at refreshing and expanding on what the students knew about both rheumatoid arthritis, and the drugs used in treatment regimens in South Africa. This was done in some measure to allay student anxiety about their first ‘real’ patient interviews. At the same time the on-line Journals were used to prompt reflexivity with respect to assumptions and understanding.

Following the interviews and the completion of draft patient care plans, a more critical element was introduced with the aim of challenging the students’ assumptions about pharmaceutical care of people with chronic illness. This process began with the review of the draft care plans, during which students were asked to explain why they made the recommendations they did with respect to their patients. At this stage observations relating to patient medicine-taking decisions were often at the level of commonsense, and explanations offered were at the level of expert-professional/layperson. Comments were product centred, even if couched in patient-centred (but not relationship-centred) language. A critical challenge was extended through the guided viewing of ‘Wit’ (Nichols 1998) and exposure to the sociological critique of biomedical approaches to healthcare. Students were then exposed to the critique of ‘compliance’ as the ideal model of patient medicine-taking behaviour. Alternative models were considered, and students given the opportunity to critique these. Pharmacy staff and an experienced pharmacist attended these sessions to provide professional perspectives. Students were given the opportunity to re-work their care plans, and to consider the approach to patient care they felt was most appropriate for support of people with chronic illness.

Contact Session	Focus
Session 1 - Introduction	Consideration of • Student expectations for the course • Lecturer’s objectives • The outcomes, assessment and evaluation of the course • Structure of the course • Following session, students to complete on-line Journal – ‘Expectations’
Session 2 - Rheumatoid Arthritis – mechanics of the disease and symptoms	Facilitated by specialist physician • Following this session, students to complete on-line Journal – ‘What’s it like’

Session 3 - Rheumatoid Arthritis – treatment options, including non-drug related therapeutic options	Facilitated by specialist physician • In the light of what they had discussed with the visiting specialist physician, students were requested to use the online Journal to identify any issues they particularly wanted addressed by the pharmacology lecturer during the next session. The concerns raised were communicated to the lecturer in advance. • Students were required to look up drugs mentioned by the physician, and familiarise themselves with the drugs names, drug forms, properties and side effects of these drugs. • Students were supplied with copies of the physicians' lecture notes and a reading on primary care for RA (Browning 2001).
Session 4 - Rheumatoid Arthritis – pharmacy response	Lecturer from Pharmacology. • Revised and elaborated on, pharmacology of typical drugs used in RA treatment regimens in South Africa (DMARDs¹ and NSAIDs²).
Session 5 - Pharmaceutical Care Plan (PCP)	In the light of what they knew about RA, and about the drug regimens in use, • Students worked through the PCP in use (Appendix B). Students had the opportunity to raise any questions they had about the PCP document, and suggest any changes or additions they felt would facilitate their interviews with their patients. • Class examined the use of the PCP as a framework for their interviews with their patients • Students supplied with copy of 'Rheumatoid Arthritis: reference summary' (X-Plain™ 2002).
Session 6 - Interviews with patients	• Students met with patients at the patients' places of work in accordance with patient preferences. Interviews lasted 60 minutes maximum. All interviews were tape recorded on audio tape. • Following the interview and the drawing up of their draft PCPs, students completed a further on-line Journal reflecting on the care plan process.
Session 7 - Pharmaceutical Care plan presentations	Students presented their care plans to the class. Class discussed each plan and highlighted items of concern and/or areas that required further investigation. A pharmacy lecturer assisted in this discussion. Students then had the opportunity of re-working the care plans, and these were then submitted to the lecturers for formative comment.
Session 8 - Preparation session for film	Identify incidents to look out for and specific themes to identify. A brief 'introduction' to each of the characters in the film was given, using clips from the film.
Session 9 - Viewing of 'Wit' (Nichols 1998)	Students reminded of previous session's discussion and then viewed film without further comment. • Students completed online Journal 'Reflections on Wit'

¹ Disease modifying anti-rheumatic drugs

² Non-steroidal anti-inflammatory drugs

Session 10 - Guided reflection on film	Review of the film identifying specific issues and themes as they relate to care of people living with chronic illness (and palliative care). • Began with a opportunity for students to comment freely on their responses / reactions. • Guided consideration using clips from the film to highlight patient / practitioner encounters and examples of discourse.
Session 11 - Disease vs. Illness – sociological concepts	Prior to the session students required to read Gwyn (2003) • Introduced concept of discourse. • Considered sociological critique of inadequacy of ‘disease’, and of the supplementary concepts of illness and sickness.
Session 12 - Chronic illness	Students had to read either WHO (2003) or Assal (1999) prior to session • Considered the concept of chronic illness from a sociological perspective. • Discussed some of the implications of chronic illness for pharmacy with reference to their patients.
Session 13 - Role of pharmacist in chronic illness care	Prior to the session students to read Watt (2000) and consider what they felt the role of pharmacist in chronic illness care should be • Group-based ‘workshop’ of the role of pharmacist in chronic illness care.
Session 14 - Critique of compliance / adherence	Prior to session students read Playle & Keeley (1998). • Considered student understanding of ‘compliance’. • Presented with summary of critiques of the concept (and underlying approach to patient care) of ‘compliance’.
Session 15 - Critique of compliance / adherence: Implications for practice?	Prior to session students to read: Brus, van de Laar, Taal, Raskera, & Wiegman (1999) and Patterson (2001). • Following on from previous session, group based discussion of problems associated with ‘compliance’ and in suggested alternatives.
Session 16 - Concordance (British Royal Ph’cy. Soc.)	Prior to session students to read Bissell, May, & Noyce (2004) • Examination of the model proposed to replace models of pharmaceutical care based on ‘compliance’. • Responding to on-line Journal exercise ‘Can Concordance work in SA?’
Sessions 17 & 18 Critique of ‘Concordance’	(A week’s break in contact sessions to permit students to catch up on readings and consider the viability of ‘concordance’) Prior to session students read Chewning & Weiderholt (2003) and Hughes, Whittlesea, & Luscombe (2002). • Considered the challenges to and possibilities of, concordance in the SA context (hospital and retail / community settings). • Group work – class considered how practical they thought the idea of ‘a concordant relationship with patients living with chronic illness’ might be. • Suggested ways of putting ‘concordance’ into practice, or proposed alternatives.

Session 18 Presentation of (re-)drafts of care plans	• Students had opportunity to present care plans to facilitate peer feedback prior to including them in their final portfolio. • Students had to argue for and defend their model(s) of patient care (compliance-disease; concordance-illness; etc.).
Course Evaluation	
Course assessment through Portfolio	(See Appendix D, Section 6).

Table 8-i: Outline of course presented to fourth year Bachelor of Pharmacy students

Formative assessment throughout the course was carried out through the on-line Journals and through feedback (peer and lecturer) on the patient care plans. The on-line Journals also served to support the students' reflexivity and to provide resources for their final portfolios. The summative assessment of the course was effected through the final portfolios (Appendix D, Section 6). Portfolios were used because they are better able to reflect professionals' understanding of 'real-life settings' than traditional assessment methods (Baume & York 2002:7). Students were familiar with the use of portfolios for assessment from their PAP course.

8.2 '...it is important for health professionals to read between the lines'

KELEKIAN [Professor of Oncology]: You have cancer. [VIVIAN stares back at him – silent, wide-eyed, almost uncomprehending] Please sit down. Miss Bearing you have advanced metastatic ovarian cancer.

VIVIAN: Go on.

KELEKIAN: You are a professor, Miss Bearing.

VIVIAN [Professor of English Literature]: Like yourself, Dr Kelekian.

KELEKIAN: Well, yes. Now then. You present with a growth that, unfortunately went undetected in stages one, two, and three. Now it is an insidious adenocarcinoma, which has spread from the primary adnexal mass —

VIVIAN: "Insidious"?

KELEKIAN: "Insidious" means undetectable at an —

VIVIAN: "Insidious" means treacherous.

KELEKIAN: Shall I continue? (Margaret Edson, *W;t. A play*. Act 1, Scene 2)³

The excerpt from Margaret Edson's *W;t* (1999: 7 – 8) is powerfully illustrative of some of the dynamics of social practice potentially present in medical encounters. Here two established academics joust for epistemological authority on ground so breathtakingly

³ While the film adaptation of this play is titled '*Wit*', the spelling '*W;t*' is correct. This forms a play on signs related to the closing lines of John Donne's Sonnet 6 of the *Holy Sonnets: Divine Meditations*, 'Death be not proud....' The Sonnet ends (in Helen Gardner's version): 'One shorte sleepe past, wee wake eternally, And death shall be no more, Death thou shalt die.' (Gardner 1972:85) Other translations of Donne have suggested a semi-colon before the final 'Death', which offers 'hysterical punctuation' as Vivian's own Professor taught her (Edson 1999:14). At that time, Vivian recalls, 'Professor EM Ashford' pointed out to her that 'Nothing but a breath – a comma – separates life from life everlasting. It is very simple really' (Edson 1999:14).

uneven that for a moment the audience is distracted from the enormity of the diagnostic revelation. Medical expertise is wielded with such unrelenting finality that the expertise of words and language, although providing the very ‘tools’ of the joust, is dismissively deemed to be ‘lay’ and thrust aside with a contemptuous silence. She is ‘miss’, he is ‘doctor’; her acknowledged expertise silenced before the medical gaze. The man who reads the woman’s body as an object of disease silences her ‘soft’ knowing with disdain. He who knows *about*, but does not (and indeed at even the most basic anatomical level, cannot) *know* metastatic ovarian cancer, draws the boundaries for she who *must* know it more completely. The instinctive grasping at firm ground by Vivian through the assertion of (her) meaning in the face of a brutal diagnosis, is granted little more than a reproachful pause by the researcher who has a subject in his sights. The literary professor’s ‘lifework... [is] “absorbed” into [a] medical framework’ in a way that results in the disappearance of her lifework (Davis in Ainsworth-Vaughn 2001: 461). The control of the interaction is firmly grasped by the ‘professional’ and the other participant placed equally firmly in the role (and status) of patient.

This encounter which forms the opening scene in ‘Wit’ , the film adaptation of Edson’s play (Nichols 1998), might slip by unnoticed, perhaps leaving us with an uncomfortable twinge that we may put down to the blunt revelation of what was, until the emergence of HIV/AIDS, the ‘scare disease’ of our time. Hearing (or reading) the words from the perspective of one who has received a terminal diagnosis, however, calls a halt to the rush through the scene; it poses a ‘What’s going on here?’ question. We become aware of a host of ‘action’ taking place beneath and behind the textual signals that present themselves as simply the ‘things people said’:

In medicine we think we live in a world of facts, a dry world that simply *happens*, but the human world is really a world of symbols. Healing cannot be stripped of metaphor, image, symbol, meaning, and interpretation. Sick people experience meaning in their lives and illnesses; they (like all of us) experience themselves as characters in a life narrative; they search for a pattern of meaning and symbol to make them whole. White coats, stethoscopes, and beepers. The rituals of rounds. The ceremonial physical examination. The MRI machine as a metaphor for burial and resurrection. The treadmill test as a Sisyphean task. Physicians, like poets, manipulate these culturally important symbols. They speak in metaphor. They tell stories. They conduct ceremonies. Like poets they influence others to change their life experience by celebrating liturgies of the word (Coulehan 1997:108).

8.3 ‘...the language they use, the look on their faces...’

The chapter title includes an adaptation of a line from the final act in ‘*W;t*’ (Edson 1999:77 – 78). Jason Posner (28 year-old oncology clinical fellow to research professor Dr Kelekian), and Susie Monahan (28 year-old head nurse) have been inserting a catheter for now nearly comatose Vivian Bearing (dying as a result of experimental chemotherapy treatment for cancer). Posner recalls his experiences as a former student reading for Vivian’s course in the Holy Sonnets of 17th century metaphysical poet John Donne. He appreciated her rigour, high standards, brilliant academic mind and knowledge, and he appreciated the complexity and rigour of Donne’s never-ending struggle with meaning and death.

JASON: Listen, if there’s one thing we learned in Seventeenth-Century Poetry, it’s that you can forget about that sentimental stuff. *Enzyme Kinetics* was more poetic than Bearing’s class. Besides, you can’t think about that **meaning-of-life** garbage all the time or you’d go nuts.

SUSIE: Do you believe in it?

JASON: In what?

SUSIE: Umm. I don’t know, the meaning-of-life garbage. (*She laughs a little.*)

JASON: What do they *teach* you in nursing school? (*Checking VIVIAN’S pulse*) She’s out of it. Shouldn’t be too long. You done here?

The excerpt, while reflecting ways in which Vivian was in part the architect of her clinical experience of medical treatment rather than care, reveals the distinction between medical and nursing education noted by Howe (2002). It also illustrates the tendency to regard the affective dimension of healthcare as something quaint, somehow lacking real academic rigour. Indeed as Jason intimates, Vivian, the brilliant academic, had little time for affect in her rigorous presentations. As an audience, however, we have been privy to two scenes earlier, when Vivian had begun to feel the enormity of her impending death in the night-time loneliness of the isolation ward.

Vivian had used the simple device of pinching her IV line closed, setting off an alarm. Susie responded, and finding the obviously distracted Vivian, sat at her bedside and chatted. As the mucous membranes in Vivian’s throat and oesophagus had been destroyed by the chemotherapy, Vivian struggled to speak and swallow. Sensing Vivian’s discomfort, Susie brought an iced Popsicle for her to suck to relieve the pain. On Vivian’s initiative, they share

the treat. During this early morning intimacy Susie raises, on her own initiative, the matter of what decision must be made in the case of Vivian needing resuscitation. Vivian reaches the poignant decision to be ‘No Code’ – an order that no attempt at resuscitation be made. In the caring intimacy between the two women, Susie casually calls Vivian ‘sweetheart’, as during what proves to be Vivian’s last lucid moments, she and Susie show an appreciation for ‘that *meaning-of-life* garbage’. In her final coherent aside to the audience following Susie’s exit, Vivian (the patient, tear-stained, grey-faced, gaunt) confides (Edson 1999:69):

That certainly was a *maudlin* display. Popsicles? “Sweetheart”? I can’t believe my life has become so ... *corny*.

But it can’t be helped. I don’t see any other way. We are discussing life and death, and not in the abstract, either; we are discussing *my* life and *my* death...

(*Quickly*) Now is not time for verbal swordplay, for unlikely flights of imagination and wildly shifting perspectives, for metaphysical conceit, for wit. And nothing could be worse than a detailed scholarly analysis. Erudition. Interpretation. Complication.

(*Slowly*) Now is the time for simplicity. Now is the time for, dare I say it, kindness.

8.3.1 ‘What’s going on here?’

The style of the preceding sections deliberately contrasts with the more conventional academic style of the Introduction to this chapter. My intention is to illustrate, in what may be a somewhat contrived manner, the way in which thinking of discourse rather than ‘language’ calls attention to disjunctions in the flow of communication. It illustrates in some way the disjunction between the logical, measured tones of the bio-medical discourse of disease, that progress through the expected sequence of complaint-diagnosis-treatment, and the interrupted patient narrative (the ‘biographical disruption’ – 4.4.1) of chronic illness. The extracts from ‘*Wit*’ afford us a glimpse of discourse at work in a way that may be less obvious in ordinary prose.

In examining the students’ ‘ways of using language of thinking, feeling, believing, valuing, and of acting’ (Gee 1990:143), that is reflected in their Journals, interview transcripts and portfolios, I have the opportunity to ask: ‘what’s going on here?’ For this purpose I propose using a critical approach to discourse analysis as a *heuristic*:

A heuristic is *a set of discovery procedures* for systematic application or a set of topics for systematic consideration. Unlike the procedures in a set of instructions ... the procedures of a heuristic do not need to be followed in any particular order, and there is no fixed way of following them. A

heuristic is not a mechanical set of steps to follow, and there is no guarantee that following it will result in a single ideal explanation. A heuristic can be compared to a set of exercises that constitute a whole-body physical workout, or a set of tools for thinking with. *A heuristic is not a theory. It is a step in analysis which may help you see what sorts of theory you need in order to connect the observations about discourse you make as you use the heuristic with general statements about language, human life, or society* (Johnstone 2002:9 Italics added).

Settling on a 'set of tools for thinking with' for this study was, however, not unproblematic. Researchers from nursing, medicine, pharmacy, sociology of medicine / health and illness, and medical anthropology recommend a range of methodologies, the majority tied to interpretivist, constructionist perspectives. Most common among these are variations on narrative research and conversation analysis (Kleinman 1998; Pilnick 1998, 2001, 2003; Greenhalgh 1999; Richman & Jason 2001; Carson & Fairbairn 2002) including the more inclusive 'constitutive ethnography' (Hargie, Morrow & Woodman 2000:62). Among studies with a more critical bent, have been calls for the use of a critical approach to discourse analysis (Gwyn 2002; Boutain 1999). My choice of a critical approach to discourse analysis was made because this expressly involves '*Seeing past happening, Hearing between words*', through the consideration of 'meaning-power relationships' involved in social practice (Chouliaraki 2002:84).

Making the choice between analytic approaches did not reduce the (super-) complexity. As Hammersley (1997) indicates, even to isolate one understanding of 'discourse analysis' is difficult. As I used discourse analysis as a heuristic, I will not attend to the extensive debate around critical approaches to discourse analysis, as this is available elsewhere (Blommaert & Bulcaen 2000; Weiss & Wodak 2002; Johnstone 2002; Phillips & Jørgensen 2002). The wide range of understandings of critical discourse analysis does mean, however, that I must clarify the understanding that I will use.

The somewhat clumsy usage of 'a critical approach to discourse analysis' is intended to signal that my usage differs from the specific approach of Critical Discourse Analysis (CDA), associated primarily with Fairclough, and Fairclough and Chouliaraki (Billig 2002; Johnstone 2002; Phillips & Jørgensen 2002; Weiss & Wodak 2002). CDA is now regarded as forming a discipline on its own (Billig 2002; Johnstone 2002; Weiss & Wodak 2002) and while this in no way negates its usefulness as an approach to the critical analysis of discourse, a commitment to CDA would arguably require the acceptance of a range of

theoretical commitments and practices, involving commitments to a ‘constructionist ontology’, which are not compatible with the critical/social realist perspective that informs this study (Chouliaraki 2002:106). Following Johnstone, my intention is to use a critical approach to discourse analysis as ‘an open-ended heuristic, a research method consisting of a set of topics to consider in connection with any instance of discourse’ (Johnstone 2002:xii).

With respect to the texts⁴ considered in this study, a critical discourse analytic approach has particular relevance. Such an approach views texts as made up of negotiated ‘discursive differences... governed by differences in power which is in part encoded in and determined by discourse and by genre. Therefore texts are often sites of struggle in that they show traces of differing discourses and ideologies contending and struggling for dominance’ (Weiss & Wodak 2002:14 – 15). It is precisely the ‘traces of different discourses’ – disease and illness in particular – that are the concern of this study, for:

It is by combining elements from different discourses that concrete language use can change the individual discourses and thereby, also, the social and cultural world. *Through analysis of intertextuality, one can investigate both the reproduction of discourses whereby no new elements are introduced and discursive change through new combinations of discourse* (Philips & Jørgensen 2002: 7 Italics added).⁵

A critical analysis of discourse thus provides a useful conceptual tool to investigate whether students reproduced biomedical disease discourse with respect to chronic illness, or evidenced elements of ‘discursive change through new combinations of’ illness, sickness and disease discourses. Such an understanding is congruent with critical/social realist ontological and social theory, which regards discourse as real and causal, and constitutive of social practice (Fairclough, Jessop & Sayer 2002). Conceptual tools:

...do not represent a self-contained edifice of theories. They are elements that may be adopted from different theoretical approaches, schools and traditions. The principle of ‘conceptual pragmatism’ applies also here: theory formation is not a process leading up to a final product valid for all times representing in itself the total truth of the world, but rather a continued development of tools and resources designed to help us understand the world (Weis & Wodak 2002: 8 – 9).

⁴ I have adopted the understanding of ‘text’ as including written and spoken discourse (including conversations and transcriptions of these), and graphics, or ‘any cultural artefact’ – the latter being something Fairclough accepts, albeit with caution (Fairclough 1995:4).

⁵ Intertextuality refers to ‘...how an individual text draws on elements and discourses from other texts’ (Philips & Jørgensen 2002: 7).

The heuristic of a critical approach to discourse analysis also offers us an insight into 'relations of power' at work, an area of particular concern in the consideration of medical professional/patient interactions (Fairclough 1989; Pilnick 1998; Hall 2003; Trevena & Barratt 2003). It is this concern for 'relations of power', and especially the concern for ways in which discourses are used to reproduce dominance in social relationships, that marks out the 'critical' concern (van Dijk 2003). Social power relations 'are based on the preferential access to or control over scarce social resources [including both material and symbolic resources] by the dominant group' – and this would include resources such as knowledge (van Dijk 2003:87). The knowledge which forms part of the expertise of the professional is such a scarce resource. Professional autonomy and power reside to some extent in controlling access to and use of that knowledge (hence one purpose of certification – Geisler 1994).

Within a pharmacist/patient relationship there is an asymmetry of knowledge when the only knowledge that is granted salience, is the knowledge of the 'expert' (Pilnick 1998). Such asymmetry is commonsensical, and as Pilnick notes, has been argued as not only inherent in the practitioner/patient relationship, but an asymmetry which the patient in many cases does not want to challenge (1998). Were this true only of the asymmetry of *knowledge* (for if the patient had the knowledge she would not need to interact with the healthcare provider (HCP)), the patient/practitioner space may be less troubling. However the problem takes on a further dimension when the control over the scarce resource of therapeutic options by the HCP is recognised. Such double control then tips the balance of power to a point where the vulnerable patient has little choice. It is these circumstances which raise the potential of patient decisions being made 'under duress' (Parks 1998:299). The risk inherent in such asymmetry is exacerbated when the HCP is in a privileged position in terms of education, economic, and social status *vis-à-vis* the patient (Parks 1998). This risk, and the rising critique of power asymmetry in health profession interactions, combine to bring about changes in the way relations between HCPs in general, and pharmacists in particular, are being envisaged by professional bodies (Stevenson, Barry, Britten, Barber, & Bradley, 2000; Candlin & Candlin 2002; Cox, Stevenson *et al.* 2002).

Pilnick argues that the long-term relationship that potentially exists between a healthcare professional and a patient living with chronic illness, provides a special case that challenges the 'commonsense-ness' of the patient acquiescing to HCP power (1998). Her argument

illustrates Fairclough's assertion that 'If one becomes aware that a particular aspect of common sense is sustaining power inequalities at one's own expense, it ceases to be common sense, and may cease to have the capacity to sustain power inequalities...' (Fairclough 1989:85). Pilnick provides clear examples of this in her research into interactions between hospital pharmacists, and patients and their caregivers in a paediatric oncology unit. Referring here to conversation analysis data from the oncology unit, Pilnick concludes:

interactional manifestations of knowledge and competence are continually negotiated by the participants in this setting in ways that tend to minimise the asymmetry that is commonly seen in the doctor/patient encounter, or indeed in other lay/professional encounters. This is evident both in the interactional dominance sense (related as this appears to be to the 'task' of the encounter for the pharmacist) and in the knowledge-based sense. Although features of knowledge-based asymmetry are sometimes evident in the data, they are rarely sustained for any length of time; even when 'new' information is imparted by the pharmacist, the ability of the patient or carer to relate this to the knowledge they already have has a minimising effect. This body of knowledge which the patient is party to in turn has an effect on the interactional dominance commonly exhibited by the professional party in lay/professional encounters (Pilnick 1998:47).

Pilnick's research suggests reasons for the critical consideration of discourse in this study, with its focus on the particular social space of health-care professional and 'patient' (3.1.4, above), in that 'language can be used to challenge power, to subvert it, to alter distributions of power in the short and the long term' (Weiss & Wodak 2002:15). Granting pharmacy students epistemological access to chronic illness discourse involves challenging the hegemonic power of the biomedical disease discourse in decisions about people – for that is what diagnosis and therapeutic decisions are. The challenge is not intended to reject disease discourse, but rather to bring it into attentive conversation with the discourse of the patient-as-person, the discourse of illness.

8.3.2 What do biomedical or illness discourses 'look' like?

There is nothing inherently 'wrong' with either biomedical or illness discourses in and of themselves. They are the discourses of communities, medical on the one hand, and 'the remission society' of people experiencing illness (Frank 1995:8) on the other. As we have noted the problem arises because discourse is neither value free nor passive (3.1.4).

The old idea that words possess magical powers is false; but its falsity is the distortion of a very important truth. Words *do* have a magical effect – but not in the way that the magicians supposed, and not on the objects they

were trying to influence. Words are magical in the way they affect the minds of those who use them. “A mere matter of word” we say contemptuously, forgetting that words have power to mold men’s [sic] thinking, to canalize their feeling, to direct their willing and acting. Conduct and character are largely determined by the nature of the words we currently use to discuss ourselves and the world around us (Aldous Huxley in Mori 2000:723).

‘Medical language... is an abstract discourse about disease and organs; it is not about patients and their experience of illness’ (Fleischman 2001:475). It is characterised by the apparently contradictory use of precise scientific language as euphemism, as a means of ‘distancing’ (signalling objectivity); it is ‘*the language physicians use...to modulate their experience of patients*’ (Mintz 1992 in Fleischman 2001:475-6 Italics in original). Fleischman refers to her own experience in which she thought the term ‘supportive care’ meant ‘to be treated with empathy and respect’, whereas it was simply ‘an umbrella term for a variety of actual therapies’ (2001:475). In the world of medical discourse ‘people living with illness are “sequestered” by the restricted role allotted to them and by their limited access to the discourse. It is in ... [the medical community]... that people are thought of not as people but rather as “patients”’ (Faber *et al.* 2003:147). In an unusual way Jaye and Wilson’s research into the experience of medical doctors who ‘become patients’, illustrates the way medical discourse positions the sick person so completely, that even when medical professionals ‘become’ patients, their membership of the medical discourse community is suspended for the duration, and they are expected to renounce agency:

Being a ‘good’ patient was described as presenting one’s symptoms as openly and honestly as possible, without offering any interpretation. It implied passivity, compliance and obedience (2003:209).

Biomedical discourse turns disease into the agent, and ‘the sufferer into the “dative/experiencer”...’ (Fleischman 2001:476). This focus on objectivity leads to a focus on quantification, and what cannot be tested / observed experimentally, is in doubt (Frank 1995; Borrell-Carrió, Suchman, & Epstein 2004; and 2.2.1 above):

It seems likely that persons suffering with chronic diseases for which objective measures are absent are particularly vulnerable to communications which appear to discredit their subjective symptomatic reports.... Where biomarkers exist, however, they can afford credibility when they confirm subjective experience but introduce considerable disbelief when they are unreliable in this regard. The relationship between objective indicators and social legitimacy seems to be a potent variable influencing the experience of individuals with chronic diseases and their communications with professional health care providers (Thorne, Harris, Mahoney, Con, & McGuinness 2004: In Press).

Growing out of the focus on disease, is the metaphor of battle, of ‘fighting disease’, but this often becomes the focus of biomedicine ‘rather than caring for the patient’ (Fleischman 2001:476). As we noted above (4.3.2) disease discourse is rooted in religious concepts of sin and failure, and the discursive slippage from ‘disease’ as evil, to the patient as sinner is subtle and easy, something evident in the discussion of compliance (5.1.2). As Martin notes, blaming the victim is closely tied to medical responsibility discourse (2001), something reflected in the compliance / non-compliance perspective on medicine practice (5.1.2 above). Frank (1995) contends that this is related to the idea of control or management, which is so much part of biomedical discourse (a patient’s diabetes is ‘well controlled because they are compliant’ or a patient’s pain is ‘controlled’ – which begs the question of how one determines what ‘controlled pain’ is). Disease is indicative of the body out of control, and biomedicine’s discourse seeks to restore predictability (regimens, compliance, tests, measurement).

Anspach (1988 in Fleischman 2001:479) describes other characteristics of the medical / disease discourse:

- *depersonalization* (focus on disease and organs and not the person; nominalization of ‘the patient’ and not ‘Ms Wilson’);
- *omission of agents* (emphasis on what, while silencing the ‘who’ and the ‘why’ through passive voice);
- *treatment of technology as the agent* (the x-ray reveals; blood tests indicate – each of which gloss over the interpretation involved) which underscores the objectivity and ‘focus on the facts’ noted above (2.2.1), and the
- *use of account markers* when referring to any accounts from the person who is ill. Account makers (‘states’, ‘reports’, ‘denies’) suggest that these remain subjective narratives until proven by objective tests. This characteristic reflects the discussion about patient ‘beliefs’ versus medical ‘science / knowledge’ (5.1 above).

Donnelly (1997 in Fleischman 2001:478) adds a further characteristic when he highlights the way medical discourse turns the ill person’s individual experience (with whatever meaning that may have for the person), into a *medico-scientific abstraction* (something Frank refers to as the ‘medical rationalization’ of their experience 1995:64). Kleinman’s comment noted earlier (2.2.1) illustrates this well, and is worth repeating for the nuanced perspective it provides:

When chest pain can be reduced to a treatable acute lobar pneumonia, this biological reductionism is an enormous success. When chest pain is reduced to chronic artery disease for which calcium blockers and nitroglycerine are prescribed, while the patient's fear, the family's frustration, the job conflict, the sexual impotence, and the financial crisis go undiagnosed and unaddressed, it is a failure (Kleinman: 1988:6).

A related characteristic of biomedical disease discourse is the *nominalization of disease*. The 'patients' in this study *have* rheumatoid arthritis. This implies that diseases are objects that can be contained in a named entity. Once a disease can be named / identified, *it* can be treated. Not the person, but the *disease* can be treated. While this would appear to militate against the identification of a person with a disease (as in 'a leper'), it has the negative effect of facilitating an approach to treatment of a condition, while ignoring the person experiencing the condition (as illustrated by Kleinman above). In summary, Sakalys contends that:

...medical metanarratives are normative scientific, social, and cultural narratives that shape the meaning of our experiences. By defining health, illness, care, and patienthood in terms of disease conditions, they tend to suppress subjectivity and the uniqueness of experience, dominating and objectifying the person who is the patient (2003:230).

Jaye and Wilson illustrate how difficult it is for medical practitioners to conceptualize the experience of illness, of 'patienthood':

Being a patient was bound up in complex assumptions about how GPs felt about their illness experience and how they perceived the role of the patient. Above all it was strongly associated with the notion of surrendering control and competence.

For a doctor to get into the patient role, it's a very unfamiliar role and it's a role in which they lose total control really. Or that is the fear thereof . . . I think you model yourself on some of your patients as well. I think . . . that you see how your patients operate and you put yourself in the role that they've shown you. (James) (Jaye & Wilson 2003:207).

Illness discourse is rooted in a completely different ontology and epistemology from that of biomedicine (2.2. and 4.3 above). In contrast to the *distancing*, *depersonalization* and *abstraction*, characteristic of biomedical disease discourse, illness discourse is *personal*, *subjective*, and *concerned with meaning*, and *experience* not *experiment* is the authorizing practice (4.3.3 & 4.4.1, above). As Gareth Williams' research into the experiences of people living with rheumatoid arthritis suggests, 'people's accounts of causation are not simply concerned with beliefs about disease aetiology *per se*, but, rather, constitute an imaginative

attempt to find a legitimate and meaningful place for RA in their lives' (Williams 1984 in Lawton 2003). Unlike biomedical discourse with its concern for control and management, illness discourse accepts contingency, and is concerned to live constructively with that (Frank 1995). 'Management' in illness discourse has more to do with shepherding resources, to carry on living in spite of the contingency imposed by disorder, than with control.

Fleischman (2001) notes an instance of the *personal* in the discourse of illness which is especially evident in the discourse of people living with chronic illness (more so among those who have been living with a condition for some time). In this instance people use the personal pronoun with reference to illness suggesting ownership of the illness. This is evident in two of the patient interviews (Students 1A & 2L) undertaken in this study. In both examples the women involved had lived with rheumatoid arthritis for at least ten years since diagnosis. Interestingly in both examples, both interviewers and respondents 'personalize' the condition:

S1A. 'K.. Do you find that your Rheumatoid arthritis effects your work in any way?

P. Not, no, not at this stage, because my rheumatoid is actually very well controlled by the drugs that I'm on, um, so (... ..) not really.

The same personalization is evident in the discourse of the person interviewed by Student 2L:

S2L. Um, does your rheumatoid arthritis affect your ability to work in any way?

P. Yes! [S2L. ok.. How..] ..Um..specifically with computer work [S2L: ok], and marking, and I' I'm, a lecturer, [S2L: ja, ja]..so, its definitely computer work, marking, um, rubbing off the board, writing on the board, because my rheumatoid is very bad in my hands, and elbows, and, effects my shoulders as well.

A further element of illness discourse is that, despite its different philosophical basis, it does colonize biomedical discourse for its own ends. People living with chronic illness frequently gain access to, and use, biomedical discourse in their interactions with healthcare workers (Pilnick 1998; Faber *et al.* 2003).

8.3.3 Considering analysis

In order to assess any evidence of students' engagement with the discourse of chronic illness, that may have occurred during the course, I have used a broad level of critical discourse analysis to consider their Journal entries and final assessment portfolios. Once again, the material

examined in this case study is purely suggestive and illustrative of an application of the theory proposed in earlier chapters.

8.3.4 Choices

Inevitably choices have to be made about text selection in discourse analysis (Johnstone 2002). Equally inevitably such choices mean more is omitted than is included, firstly because analysis can only be of ‘records of discourse’ rather than actual oral discourses. This implies that all discourses that occurred during the course (let alone those that took place outside the formal contact sessions) are not available for analysis. Secondly, the very act of transcription (of interviews in this case) inevitably gives the text ‘boundaries’ – transcription choices cannot include every nuance, visual clue, and tonal gradation (Johnstone 2002:19).

Further, texts are shaped by context. The texts available for this study are part of an educational course, a required elective which students had to pass in order to obtain their degree. Students therefore had to be given explicit assessment criteria (Appendix ‘D’), which inevitably influenced the texts they produced. The Journals were a course requirement, but were not part of the summative assessment. These were used to help students develop reflexivity, and to provide support for their writing up of their portfolios which formed the summative assessment task. The Journals were accessible only by the student concerned and myself, but the students did know that the Journals were being read and commented on by the lecturer who would be one of the assessors for the course (the other assessor being the Pharmaceutics professor who attended the course as an advisor).

The available texts were thus restricted to on-line student reflective Journals, interview recordings and resultant transcripts (made by myself), plus the summative assessment portfolios. These are of course restricted to the texts produced by the seven students who agreed to participate in the study (7.1 above), and are further restricted to selected portions of the available texts with respect to Journal entries, although the full Journal entries are available on the enclosed CD, with names removed. To these sources was added the evaluation report from the independent evaluation carried out at the end of the course (Appendix ‘H’).

8.3.5 Confidentiality

Special precautions have had to be considered in the case of the transcripts of patient interviews and the Pharmaceutical Care Plans (PCP). In order to maintain confidentiality, only excerpts from these texts will be recorded in the thesis, and mostly relating to the words reflecting the students' speech. Owing to the nature of small town life in the university town in which this study occurred, and to the fact that two of the patients are university staff members, neither full transcripts nor completed PCPs can be provided in the Appendices. The usual conventions relating to changing names will not provide sufficient protection, as contextual factors can in some cases lead to easy identification of patients, healthcare practitioners, and organisations referred to in the interview transcripts. Similar precautions have been applied to student Journal entries, which make reference to patients in such a way as to permit possible identification.

8.3.6 Framing the analysis

Johnstone (2002:9 – 18) proposes six statements which provide a structure for a heuristic of discourse analysis. These six statements (a – f, below) help frame the focus of the 'what's going on here' questions that must be asked of the texts to consider the discourses that may be present. All references in (a) – (f) are to Johnstone (2002) unless specifically noted otherwise.

a) discourse is shaped by the world, and discourse shapes the world

Discourse arises out of, and refers to a world that exists outside of discourse, 'the worlds of the creators and interpreters of texts' (2002:10). 'But discourse shapes the phenomenal (experienced) world in turn, since... it is through language that we come to categorize' (2002:61). Categorization is a central feature of healthcare discourses, but while categorization suggests certainty and 'identification' (with implicit links to the idea of 'identical', implying that the *name* equals the *reality* to which it points), categories are contested. Categorization is fundamental to diagnosis, and as is clear with respect to rheumatoid arthritis, diagnosis is both difficult and complex, and naming a set of signs and symptoms 'rheumatoid arthritis' is uncertain (Lee & Weinblatt 2001). Once named, however, people 'have' the condition (Johnstone 2002:33), and therapeutic decisions are made based on the naming: their worlds have been shaped by biomedical discourse. Words, argues Johnstone, are not innocent. 'Like other words, "nature" is not "just a word" that refers to something that already exists in the world, but rather an idea which is created and contested as people name it and talk about it' (2002:30). This is not to deny the referent to

which the sign refers, but it is to assert that what different people ‘make of’ that word will rarely be the same.

Choices we make about how to talk are shaped by ideology rooted in our worldview. This is well illustrated in the ‘diagnosis’ excerpt from *Wit* (7.2 above) reflecting the interaction between *Doctor* Kelekian, and *Miss* Bearing. Kelekian seems to acknowledge Bearing’s learning (‘You’re a professor, Miss Bearing?’), although the ‘Miss’ rather than the professional honorific of ‘Professor’ weakens that acknowledgement. Initially it appears as if he were suggesting that with her intelligence she will understand what is to come, and he then proceeds with a highly technical description of the disease which is Vivian’s illness. Despite this apparent acknowledgement of her education, the moment Vivian asserts her (legitimate) understanding of a word (and recall, she is a professional in the use of language), Kelekian rejects her knowledge as worthless. Her attempt to challenge his emotion-less use of ‘insidious’ is brushed aside with a tight-lipped pause, a brief silence. ‘Silences’ as ‘discursive absences’ become important as ‘Struggles over power and control are often struggles over whose words get used and whose do not and over who gets to speak and who does not’ (2002:59).

One of the most significant ways in which biomedical discourse exerts ideological influence in healthcare practice, is through the use of the scientific discourse practice of downplaying agency and transactivity (Johnstone 2002). The previous sentence provides an example: I have ‘removed’ the actors (those who use biomedical discourse) through the use of nominalisation. Transactivity is downplayed by my omission of ‘origin and receiver’ (2002:46). A further example is provided in the following excerpt from the *Journal of Clinical Pharmacy and Therapeutics* offering a comprehensive review of literature on ‘medical non-compliance’:

Compliance is a very important issue in medical care for three main reasons. Medical non-compliance imposes a considerable financial burden upon health care systems. Compliance to treatment, to advice or to lifestyle changes is the key link between process and outcome in medical care. Lack of regard for levels of compliance may have a major impact on conclusions drawn from clinical research, especially drug trials (Vermeire, Hearnshaw, Van Royen, & Denekens, 2001:331).

At a quick glance the uninitiated may believe that this article has to do with members of the medical profession failing to follow regulations or instructions with regard to treatment protocol – after all, the passage refers to ‘medical non-compliance’. It is, however, the

compliance of the ‘missing’ person living with chronic illness, that is later identified as responsible for ‘a considerable financial burden’. Even the term ‘compliance’ does not clearly identify who is compliant to what and whom, and why this should be so.

My intention here is not to critique ‘scientific discourse’ in biomedical literature, but rather to illustrate the way in which this discourse serves to ‘shape the phenomenal (experienced) world’ of biomedicine. As I have argued (Chapter 5), there is a substantial amount of literature that challenges the usage of ‘compliance’ (acknowledged by Vermeire *et al.* 2001) but even beyond that ideologically loaded concept, the authors’ discourse in the excerpt has the effect of eliminating agency and transactivity. This is especially ironic (and self-defeating), when we recognize that the article is specifically concerned with patient agency. When this discourse is translated into the healthcare practitioner’s thinking about a patient, then precisely because discourse shapes the world, it impacts on the way the healthcare practitioner categorizes (views) the human person standing before her / him.

b) discourse is shaped by the possibilities and limitations of language, and discourse shapes language

‘Texts and their interpretations are shaped by the structural resources that are available and the structural choices text-builders make.’ These include conventions (2002:12). One of the problems experienced by patients is that biomedical discourse is frequently inaccessible, and effectively inhibits a patient’s ‘shaping of the phenomenal world’ in which they now must live, by withholding information. Chronically ill people become shadowy presences on the fringe of the biomedical discourse community, while decisions are made about them, in their presence, but excluding them through (perhaps unconscious) ideological control (Assal 1999). As Pilnick (1998) and Toombs (1995; 1996) illustrate, people living with chronic illness frequently challenge that control by ‘finding out’ what the medical terms mean, and using the terminology themselves.

c) discourse is shaped by interpersonal relations among participants, and discourse helps shape interpersonal relations

Such relations include power relations (adult/child; educator/student; pharmacist/patient) and relations ‘among the speakers, audiences and overhearers [sic] who are represented in the texts, [and]... among speakers and writers, and audiences and overhearers who are involved in producing and interpreting texts’ (2002:14). Power relations refer to

asymmetrical relationships, of which the HCP / patient relationship is an example. Power in interpersonal relations is made up of both institutional and situational power, and HCPs have both, even though as we have noted, the pharmacists' institutional power is under threat. People find ways of negotiating power within asymmetrical relationships, in order to obtain what they want (or as near as possible), sometimes by seeking to control situational power in order to reduce the influence of institutional power (for example the rise of the 'healthcare consumer' who can exercise her/his power by going elsewhere). Johnstone notes a particular nuance of power in human interaction: 'power is not necessarily dominance, but rather more like agency: a person's ebbing and flowing contribution to shaping the activity at hand' (2002:113).

A further dimension of interpersonal relationships to which Johnstone refers, has particular bearing for this study: the influence of 'social roles and discourse roles' (2002:119). Recalling the discussion of the meaning of 'sickness' (4.3 & 4.3.4 above), one example of social roles would be of the role society accords (or imposes) on a sick person, and the concomitant role of the healthcare professional as 'healer'. Each social role has discourse role expectations, and as Johnstone notes: 'Breaking the conventions for a discourse role can be an effective move, because it can serve to remind people in the situation what usual expectations are' (2002:119). I would add that it can also serve to remind people of what may be 'unusual expectations' of people who want to signal that they are not content to remain within a predefined role. Examples of this are present in Pilnick's data from pharmacist/caregiver interactions, in which a caregiver 'breaks the conventions' by deliberately using technical language when a new pharmacist 'talks down' to her regarding her child's medications (Pilnick 1998:43), and secondly where a parent explicitly challenges the pharmacist's refusal to acknowledge his knowledge of his child's drug regimen, by confronting the pharmacist: 'Why didn't you just say so?' (Pilnick 1998:44). Such breaks with conventions reflect human agency for, while 'people's linguistic resources and choices are limited by the ways in which their behaviour forms part of the whole ecology of human social life, participants in discourse are individuals who make decisions, and these decisions are fundamentally creative...' (Johnstone 2002:133).

d) discourse is shaped by expectations created by familiar discourse, and new instances of discourse help shape our expectations about what future discourse will be like and how it should be interpreted

“Intertextual” relations between texts and other texts enable people to interpret new instances of discourse with reference to familiar activities and familiar categories of style and form’ (2002:15). More simply: past experiences of discourse(s) colour the way we engage in other discourses, and shape what we expect in an interaction within a specific discourse setting or community. So for example, the limited depth of interactions that have occurred between pharmacists and patients in the past (and continue in the present – Dyck, Deschamps & Taylor 2004: In Press) will exert an influence on how patients expect to interact with pharmacists. Intertextuality also describes the incorporation of aspects of biomedical discourse into illness discourse.

Another aspect of prior discourses is the concept of *register* (a pattern of both vocabulary and grammatical features associated with a particular, but regularly occurring, context, such as legalese in court room interactions). In the context of patient/pharmacist interaction, it would appear more likely that features of register would be apparent in the technical jargon of the pharmacist, than in the usage of patients, but in the case of chronic illness people often make use of the short-hand of the medical register for all kinds of reasons (Pilnick 1998).

A regular feature of chronic illness discourse is the use of *plots*. Kleinman (1988), Frank (1995) and others describe the importance of plot in illness narratives, as plots act as ‘semantic scaffolds of creating worlds in discourse. They are prior texts for histories, lives, and other narratives’ (Johnstone 2002:161). As chronic illness is (frequently) experienced as biographical disruption, the illness narratives people present to the healthcare practitioner are never mere ‘patient histories’ – they are frequently ways of making sense of the new dimensions of the world in which the chronically ill person must now live.

e) discourse is shaped by the limitations and possibilities of media, and the possibilities of communications media are shaped by their uses in discourse

Ranging from fonts and punctuation, through use of graphics and electronic media, we are limited and extended by what is available. Simple examples of this would be to compare the texts involved in SMS messages, e-mails, telephone conversations, and the like.

f) discourse is shaped by purpose, and discourse shapes possible purposes (2002:17)

‘All discourse is both adaptive and strategic. Everything people say arises out of [their interpretation of] the existing situation; opportunities for text-building are always hugely limited by the predictable ways in which new discourse has to be part of past discourse and ongoing discourse’ (2002:196). In an interaction with healthcare professionals who use biomedical discourse, patients are effectively second-language speakers. The excerpt from *Wit* (7.2 above) involving *Dr Kelekian* and *Professor Bearing* (or, *Miss Bearing*, as Kelekian would have it) illustrates this ‘limitation of text-building’. However, as Johnstone notes, ‘Any choice a speaker makes about how to word or perform an utterance can function as a cue about how it is meant to be interpreted...’ (2002:204). Such choices may be simple conventions such as when using ‘discourse markers’ in building an argument in an essay (because, therefore), or they may be ideological, illustrated in Jason Posner’s ‘Listen...’ which precedes his silencing of Susie Monahan’s ideas of ‘that meaning of life garbage’ (7.3 above).

8.3.7 Framing the questions

Unlike the conventional ‘open – ended’ approach in the use of CDA, my concern here is simply to identify evidence of the biomedical, BPSM, BPSP and / or illness discourses which may be present in the students’ texts. In particular, my purpose in analysing the texts produced by students participating in the course, is to look for evidence of epistemological access to the discourse of illness. Such access may facilitate the type of engagement between patient and pharmacist looked for in the concordance approach to pharmacist / patient interactions (5.1.4). Gee has argued that access to a discourse comes primarily through participation, supported to some extent by teaching (3.1.4 above) – my question is thus: **Is there evidence that the (brief) participation in the discourse community of chronic illness, supported by the experiential learning of the Elective, granted students access to the discourse of illness?**

I will need to identify elements of that discourse, as well as elements of the disease discourse of biomedicine, and see if students demonstrate an awareness of the ‘... particular aspect of common sense ... sustaining power inequalities at... [their and their patient’s]... expense’, because as Fairclough suggests, the discourse that permits common sense then ‘ceases to be common sense, and may cease to have the capacity to sustain power inequalities...’ (Fairclough 1989:85 – above 7.3.1). For as I noted above (7.3.1), following

Philips and Jørgensen: ‘It is by combining elements from different discourses that concrete language use can change the individual discourses and thereby, also, the social and cultural world. *Through analysis of intertextuality, one can investigate both the reproduction of discourses whereby no new elements are introduced and discursive change through new combinations of discourse*’ (Philips & Jørgensen 2002: 7 *Italics added*).

Johnstone’s six statements provide ‘a heuristic approach to discourse analysis’ (2002:227). ‘Heuristic’ has the essential meaning noted above: ‘A heuristic is *a set of discovery procedures* for systematic application’ (7.3.1), but heuristic also suggests using ‘reasoning from past experience since no algorithm exists or is relevant’ (Collins English Dictionary 1979). The latter import is present in my approach to discourse analysis, which is informed by critical realism, whereas the majority of approaches have been developed assuming constructionist ontological perspectives. Critical realism extends the signified (concepts) and the signifier (words or images) of discourse theory, to include the referent (‘that which we speak or write about’) (Sayer 2000: 36). As Sayer argues, illustrating the critical realist understanding of discourse:

Whether the patient is in the hospital is not reducible to a matter of discursive definition, for once one has provided definitions (within a wider discourse, of course), one is still left with the empirical question of whether the thing defined as ‘patient’ is in the thing defined as ‘hospital’. The discourse-dependence of reference does not mean that we can never distinguish between successful and unsuccessful references (2000:38).

In the light of this understanding of a critical, heuristic approach to the analysis of the texts under scrutiny, and the essential question posed above, the following table sets out the questions that Johnstone’s six statements suggest for this study (Table 8- ii):

Statement	Possible questions
a) discourse and the world	How does the discourse used by the respondent constrain the way s/he describes, explains and categorizes things within this context? Is there evidence of any ideology (asymmetry of power) that informs/maintains these categorizations? If so, what ideological perspective(s)? Is there evidence of congruence between their discourse and their way of acting in the light of such description, explanation and categorization? Does s/he use a particular discourse to reproduce or transform what s/he is presented with? In what ways, if any, and by whom, is discourse used to subvert ideology?

b) discourse and limitations of language	How does the respondent use (or ignore) 'rules' in discourse to facilitate communication, and to 'comment on what we are doing at the moment so as to align our grammars with those of our [interlocutors]' (2002:228)? What kind of alignment is taking place – is it acquiescing or challenging?
c) discourse and interpersonal relationships	In what ways does her/his discourse reflect the understandings of social relatedness present in the text? (eg. Pharmacist / patient; doctor / pharmacist) How does his/her use of discourse reflect power and 'face' in the texts? How does the respondent construct the way they see themselves, or see that they need to be?
d) discourse and intertextuality	What evidence is there of past understandings influencing the discourse of the text? How has the experience of new situations facilitated / constrained ways in which participants have engaged with other discourses?
e) discourse and media possibilities	Is the newness of the text(s) (e.g. PCPs; Journals, Portfolios) reflected in the discourse? How? What does this suggest?
f) discourse and purpose	What discourse marking strategies have participants used? What discourse strategies have they used to align themselves with the purpose(s) of others, or to align others with their purpose(s)?

Table 8-ii: Analysis questions based on Johnstone's six heuristic statements (adapted from Johnstone 2002:227 - 238)

8.4 Analysing the texts

I shall use the framework suggested by these statements and questions to frame my analysis. The analysis was carried out using *QSR NVivo®* (2002) computer-aided qualitative data analysis software to code the electronic texts (the on-line journals, converted from HTML to Rich Text Format to facilitate the use of *NVivo®*; the transcriptions of the patient interviews; and the 'Reflection Statements' from the final student portfolios). In each case the texts were initially coded using a deductive approach, looking for pericopes which reflected student use of biomedical discourse, or the use of a relationship-centred discourse. A second inductive coding was carried out using *in vivo* coding to identify trends or characteristics in the student texts, and these were then re-examined a third time to see how they related to the two healthcare perspectives. Where connections were identified these were further coded (without removing the initial coding), to show their relationship to the relevant healthcare discourse. Those sections which did not appear to relate to either of the two perspectives,

(for example, sections that referred to their experience of the course) were not included in this analysis, but were compared with the overall course evaluation to ensure that student experiences of the course were considered for the study recommendations.

At this stage individual student texts from later in the course were compared with those from the beginning of the course (using the viewing of *Wit* as a dividing point) to see if signs of a shift in discourse related to patient care were present. The students' pre-interview Journal texts were compared with the reflections contained in their end-of-course portfolios, as the primary sites for identification of a shift in access to discourse. Attention was also given to earlier Journals to which students had returned in order to add / edit comments (reflected in 'Last edited' date in on-line Journal). The use of both deductive and inductive coding is in line with critical approaches to discourse analysis (Wodak 1999). The codes used in the final coding are listed in Table 8-iii (note that "/" indicates a sub-code):

Code	Interpretation
Biomedical	Reductive; conflation of observable 'facts' with 'reality' / 'truth'; claims objectivity / value-neutrality
/Compliance	Refers to patient behaviour that accords with HCP's instructions; views patient as passive; patient knowledge characterised as 'beliefs' / HCP as rational
/Disease	Reflects disease discourse (the problem from the practitioner's perspective)
Illness	Reflects illness discourse (refers to and values the patient's experience of the disorder(s))
Professional-expert	Reflects asymmetry of power
Professional-trust	Reflects attempts to balance power; relationship-centred
Concordance	Recognizes negotiated nature of supporting optimal patient medicine-taking decisions
Shift	Reflects understandings not initially present
/Confused	As above but reflects unsettledness about this
/Illness awareness	Reflects awareness of patient's experience
/Patient knowledge	Recognition of patient's knowledge as valued / valuable
/Troubling certainty	Recognition that student's prior assumptions inadequate
BPSP	Reflects an understanding of the BPSP congruent with the relationship-centred model proposed by Borrell-Carrió <i>et al</i> (2004)

Table 8-iii: Explanation of coding used

What follows is to be read under two caveats suggested by Johnstone (2002). Firstly that discourse analysis moves from the text outwards – there will always be surprises. Secondly:

When you study a text or a transcript, you are always in some sense trying to understand it. But to understand a text completely would be to arrive at its true meaning, and, since meaning is always particular and situational (in other words, what a text means depends on who is uttering it, why, when, who is listening, and so on), this is impossible. Analyses of discourse are

always partial and provisional. Any particular utterance presupposes an entire world... (2002:237 – 8).

All illustrative extracts from student texts are as presented with no grammatical or spelling corrections. Note also that the on-line Journals permit an informal e-mail type genre where formal academic language use was not expected.

It is important to recognise that students choosing this Elective did so because they were concerned about the complexity of medicine-taking decisions in people living with chronic illness, which would suggest a consciousness of the failure of present practice, for example:

- Other expectations i have of this course are, learning to effectively counsel patients with RA, how we can assist the patients to be compliant with their treatment, not only regarding their medication, but also regarding issues like diet and exercise (Student 1A, Response to Journal 2, ‘Expectations and Concerns’).
- I am expecting that this course shall increase my awareness regarding the treatment/counselling/approaching of a patient with not only Rheumatoid Arthritis, but the ability to extend this to any form of chronic illness (Student 3C, Response to Journal 2, ‘Expectations and Concerns’).
- I expect to come away with practical knowledge and skill in order to draw up a drug management plan to help my chronic illness patients to take their medicine correctly and recieve the full therapeutic benefits (Student 7K, Response to Journal 2, ‘Expectations and Concerns’).

8.4.1 What discourse is predominant in student texts prior to, and including, the first interview with the patients?

The students completed the first on-line Journal task (“Starting Point”)⁶ prior to the first contact session. The first Journal task had two purposes. With respect to *learning*, it was intended to give students the opportunity to consider their understanding of the fundamental concepts in the course, to provide ‘hooks’ on which to connect the concepts and practice they would be exposed to during the course. In addition it provided me with a feel for what degree of reflexivity and conceptual understanding the students brought to the course. Lastly it gave opportunity for students to ensure that the technical aspects of using the LMS were in place, and that they were able to login. This was important as the use of an LMS was

⁶ On enclosed CD: /Course_Resources/Elective_Journal_Task_Pages/Journal_1_Starting_Point.php.htm

completely new to them. With respect to the *research*, their responses provided me with a ‘baseline’ of their understanding of the three central concerns of the course: chronic illness, the role of the pharmacist, and their prior engagement with the discourses of ‘disease’ and ‘illness’. The task required each student to respond to three questions:

1. What do you understand by "chronic illness"?
2. What do you understand the role of the pharmacist to be in relation to people taking chronic medicines?
3. What do you understand by the terms "illness" and "disease"?

Table 8-iv, below, provides a brief overview of analysis coding for Journal Task 1 (using the understandings outlined in Table 8-iii, above). Unsurprisingly there are few texts which reflect any shifts in understanding, with the exception of one coded ‘Shift/confused’ (see below for further discussion). The four shaded columns relate to coding of biomedical discourse, showing that 17 of the total 28 coded items were indicative of this perspective. Ten of the remainder suggest elements of discourse supportive of a relationship-centred approach, and one coded item indicates a student expressed confusion relating to new awareness of an alternative discourse.

Analysis Code	Coded text	Interpretation
Biomedical	2	Reductive; conflation of observable ‘facts’ with ‘reality’ / ‘truth’; claims objectivity / value-neutrality
/Compliance	7	Refers to patient behaviour that accords with HCP’s instructions; views patient as passive; patient knowledge characterised as ‘beliefs’/ HCP as rational
/Disease	0	Reflects disease discourse (the problem from the practitioner’s perspective)
Professional-expert	9	Reflects asymmetry of power
BPSP	4	Reflects an understanding of the relationship-centred Biopsychosocial practice approach (holistic, relationship-centred)
Professional-trust	2	Reflects attempts to balance power; relationship-centred
Illness	1	Reflects illness discourse (refers to and values the patient’s experience of the disorder(s))
Concordance	3	Recognizes negotiated nature of supporting optimal patient medicine-taking decisions
Shift	0	Reflects understandings not initially present
/Confused	1	As above but reflects unsettledness about this
/Illness awareness	0	Reflects awareness of patient’s experience
/Patient knowledge	0	Recognition of patient’s knowledge as valued / valuable
/Troubling certainty	0	Recognition that student’s prior assumptions inadequate
TOTAL ITEMS	28	

Table 8-iv: Coding Table for Journal Task 1

The responses from two of the seven students (1A, 3C) reflected some awareness of the complexity of chronic illness: although Student 1A used nominalizations that serve to

depersonalize the person living with illness. Student 1A's use of 'that' ('Patients that are chronically ill...') could be further indication of objectification of the patient, but such an interpretation should be considered with caution, as such a usage is colloquial and reflects the 'spoken language' form characteristic of the email genre.

Chronic illness means suffering from disease or illness that is long term and in most cases has no cure. Patients that are chronically ill, can also suffer from more than one chronic illness, resulting in these patients being on complicated drug regimens. These patients usually suffer from a lot of side effects and in most cases feel most sick from the side effects and drug interactions, than feel sick or ill from the disease itself (Student 1A).

And

A chronic illness is a form of illness which cannot be cured, only managed- hence, one needs to try and alleviate symptoms or attempt to reduce pain- whatever the necessary measures to make the person maintain a relatively normal life. As such, a chronic illness may be described as an illness which affects the individuals' normal lifestyle and to which they may have to adjust e.g.) [sic] diabetes, hypertension, asthma...or as far as a physical disability. A chronic illness may not necessarily be seen by the outside world -i.e. depression- yet it is affecting the life of the individual and their normal daily routine (Student 3C).

While both students indicate awareness that illness has wider life-style complications, and that the sick person's experience extends beyond simply a series of signs and symptoms (a disease), Student 3C most clearly provides recognition of the 'personal-to-holder' experience of chronic illness. This student goes further in highlighting what was at this stage in the course, an unrecognised formal sociological concept: the disjunction between an individual's experience and society's recognition of that experience (illness vs. sickness):

'A chronic illness may not necessarily be seen by the outside world -i.e. depression- yet it is affecting the life of the individual and their normal daily routine'.

Student 1A's recognition of the impact of medication side effects (ADRs or DRPs – 5.1.1), does show some recognition of the individual experience central to the illness discourse, although this is not explicit. Student 1A's use of 'patient' as opposed to Student 3C's use of 'person' illustrates the distancing tendency of biomedical discourse, compared with illness discourse's concern for individual agency. This illustrates the different ways the biomedical and illness discourses reflect their relation to the world (Johnstone 2002 and 8.4.3 above), where the use of 'patient' maintains the essential biomedical ideological categorization of the passive, compliant seeker of help, over against the recognition of agency and individuality inherent in illness discourse.

In response to the second question in the Journal task (the role of the pharmacist), Student 3C ‘falls back’ into a biomedical approach, resorting to what is in effect, her primary professional discourse (Gee 2003). With respect to Johnstone’s third analytic question (‘discourse and interpersonal relationships’ – 8.4.1 (c)), Student 3C retains a professional-expert relationship marked by the nominalizations ‘pharmacist’ and ‘patient’ (although the use of these terms could be a default student response to an assessment task).

1 Where a patient is taking medication for a chronic illness, the pharmacist
 2 must first understand that the patient may be embarrassed about their
 3 situation or feel uncomfortable about other people knowing. The
 4 pharmacist should then take care when dealing with the patient, not
 5 making a fuss about them but ensuring that they receive their medication
 6 confidentially i.e. not loudly proclaiming they are out of stock etc. and
 7 ensuring the matter is not discussed openly with other staff etc. Hence, all
 8 the normal ethical contracts between patient and pharmacist should be
 9 enforced. The pharmacist should be empathetic to the needs of the patient,
 10 not treating them as abnormal or alienated or attempting to 'know' or relate
 11 to what the patient is going through- but rather to attempt to understand.
 12 The pharmacist should judge the situation with the patient, where
 13 sympathy or pity may not be ideal and to rather just listen to what the
 14 patient wants. On that note, when issuing the patient medication; the
 15 pharmacist should question (not pry) into the lifestyle of the patient and in
 16 so doing attempt to offer them the best medication regimen possible; this
 17 may be that the patient cannot swallow tablets easily and so injections
 18 would be better suited etc. Once the ideal medication is prescribed, the
 19 pharmacist should discuss with the patient the dosing regimen and ensure
 20 the patient understands that the pharmacist would like to help, and so if
 21 there are any problems- to feel welcome to chat to the pharmacist about
 22 their medication. The pharmacist should emphasize the benefit of
 23 adherence to the medication and describe side effects or drug interactions
 24 which may be anticipated, and how to deal with them. The pharmacist
 25 should allow the patient to ask questions or deliver their thoughts on the
 26 medication. The pharmacist should attempt to ease the patient into
 27 thinking that the drug regimen can just be considered a 'normal' part of life.

The extract reflects the biomedical / professional-as-expert perspective ‘embedded’ (Fairclough 1995:15) in the discursive practices of the BPSM (Marks 2000; Cornish 2004; 2.2.2.3 above). Student 3C notes, for example, that the pharmacist must take care ‘when *dealing* with the patient’ (line 4). There is also a sense in which this example could reflect an approach to pharmacy practice that was not coded – namely an approach that rests on the business model of the pharmacist’s role, in that one usage of ‘deal with’ implies ‘to do business with’ (Collins English Dictionary). In either sense, the individual person is objectified, although in different ways. Although Student 3C is generally very sensitive to

the ‘patient’s’ needs, the student nonetheless argues that the pharmacist ‘should *emphasize the benefit of adherence* to the medication’ but merely ‘*describe* side effects and drug interactions’ (lines 22-23). Student 3C’s discussion of medicine practice (lines 15 – 22) is framed in the discourse of patient centred adherence, more akin to the BPSM than the modified BPSP. For example the pharmacist should ‘*offer them* the best medication regimen possible’, rather than (for example) ‘advise the person about the medications, and discuss....’ The student ends with ‘The *pharmacist should attempt to ease the patient into thinking* that the drug regimen can just be considered a ‘normal’ part of life’ (line 27), which is highly suggestive of a hidden agenda of biomedical compliance.

A similar mix of discourses is present in other students’ responses to part 2 of the first Journal exercise. Student 1A first proposes that ‘one of the main roles of the pharmacist is the ability *to be able to empathize and understand*’ and eleven lines further: ‘Another very important role a pharmacist has to play, where chronic patients are concerned is *encouraging compliance and finding effective ways for chronic patients to be compliant*’ (Italics added). This is followed immediately by: ‘For chronic patients to take medicine everyday is a negotiation’ – reflecting clearly the relationship-centred discourse of the revised BPSP and concordance. Student 4L’s response moves from BPSM / Adherence through the empathetic understanding of a relationship-centred illness discourse, briefly to biomedical compliance and ending with a BPSP focus⁷:

Ensure proper use of the medication, ensure the availability of the medications. Give the patient education with regard to side effects of the drugs and who to use them. They should give support to the patient and reassurance. They should monitor patient compliance and maintain good relationship with their patients (Student 4L).

In the extract referred to above (lines 1 – 27), Student 3C reflects an awareness of illness (the experience from the patient’s perspective), emphasising confidentiality and sensitivity on the part of the pharmacist (lines 6, 7), and the importance of empathy in seeking to understand the patient’s perspective (lines 9 – 11). The BPSM discourse is also reflected in the other students’ Journal responses to Task 1:

- ‘[Pharmacists]...should monitor patient compliance and maintain good relationship with their patients’ (Student 4L);

⁷ This student is a speaker of English as an alternative language.

- ‘The major role of the pharmacist in dealing with chronic illness is going to be the problem with drug compliance. The pharmacist will play a role in counselling the patient in order to ensure compliance’ (Student 5A);
- ‘The role of the pharmacist is to ensure that the patient is adherent with regard to their medicine-taking behaviour, and also to counsel and be supportive to the patient’ (Student 6F);
- ‘Ensure that the patient understands his illness and is taking their medication properly to receive the full therapeutic benefit’ (Student 7K).

The traces of BPSM discourse are illustrative of intertextuality – the way the students draw on prior texts to which they have been exposed (Fairclough 1989; 1992; Johnstone 2002) – present in the creation of the journal texts. The BPSM discourse is the underlying discourse found in the Rhodes University Pharmacy Faculty PAP course documentation (above 6.2.3 and Futter 2002a; 2002b; 2004; Mansoor 2003). For example, in the guide which all of the students received as part of the preparation for their Community Experience Programme (CEP), Mansoor states: ‘Comprehensive pharmaceutical care can be considered as the process whereby pharmacists ensure the “appropriate use of medicines” by individual patients’ (2003:2 *Italics added*). Indeed one student explicitly makes this connection in Journal 2’s task:

I realise that this course will require a lot of extra readings and research, but am anticipating that it will correlate a lot with what we learn in Pharmacy Administration and Practice, under counselling and managed care systems (Student 3C, Response to Journal 2, ‘Expectations and Concerns’).

Further indications of intertextuality involved the texts of the overtly biomedical pharmacology course (present in the following extracts from Students 3C’s and 5A’s responses to Journal task 3), and the personal experiences of the students (exemplified in an extract from Student 1A’s response to Task 3)⁸. This task followed two lectures on aetiology, diagnosis and treatment by the specialist physician who advised on the study, and two on drugs used in the treatment of RA by a Faculty lecturer from the pharmacology department (herself a medical doctor). Student 3C’s response was multiple coded *Biomedical* (lines 28 – 32) and *Shift/Illness awareness* (lines 35 – 38) (*Italics added*):

⁸ Task 3’s framing questions were: 1. Has your understanding of RA changed in any way, and if so, how? and 2. What do you imagine must be the most difficult aspect of living with Rheumatoid Arthritis?

28 We dealt with Rheumatoid Arthritis treatment in our Pharmacology
29 Course in our third year of studies. However, we did not deal with the
30 patient aspects as much as the mode of action of the medication and
31 pharmacokinetics. Focusing on the patient aspect, [w]e understood what
32 signs and symptoms to look out for, the checklist of problems etc, but not
33 the idea that there was the delayed onset (18 months before symptoms of
34 inflammation/stiffness), fatigue or the degree of pain that the patient may
35 be experiencing, for example. *My understanding toward the reasons for*
36 *patient complaints and the desire they may have to keep trying to find the*
37 *right medication for them, as well as non-compliance/adherence has*
38 *changed as I begin to see the patient by putting myself in their situation.*

The following extract from Student 5A's response, pointing again to the discursive practices of pharmacology as providing a basis for current interpretation, was coded *Shift/Troubling certainty*: 'I think we had quite a good understanding of RA from our pharmacology backgrounds, but this sort of puts a human face to it...'. Student 7K's response (coded *Shift/Illness awareness*) also reflects a new awareness of the person-behind-the-condition, but remains within the discourse of the BPSM: 'It [my understanding] has Changed a great deal, from just being a word, a diagnosis, to an actual problem connected to people it's become more real and I understand alot more about it [sic]'

Student 1A's response, also multiple coded (*Biomedical/Disease*, lines 40-41; *Shift/Illness awareness*, lines 41-43; and *Illness*, lines 43-53 Italics added), reflects the incorporation of personal experience and the illness narratives (Frank 1995) of people living with chronic illness:

39 Yes, my understanding of Rheumatoid Arthritis has changed. I now have
40 a better understanding of what the disease is all about and I have a better
41 idea of what signs and symptoms to look for. *I definitely have a better*
42 *understanding of what these patients are going through and I have learnt*
43 *the importance of being able to empathize....* [Omitted section].... Many
44 patients become disabled in on way or another and have to modify their
45 lifestyle in order to accommodate for this. This often makes patients feel
46 worthless and especially helpless because in some cases, what they are
47 going through cannot be helped. I know an RA patient, who has developed
48 bad RA in his legs, due to trauma from a car accident. It now takes him
49 like about triple the time to walk down the stairs than it used to. This
50 patient was a very active person is and still is, but the frustrations and
51 restrictions are what is killing him psychologically and mentally. The fact
52 that these patients become restricted and dependant to some extent is what
53 I feel is most difficult to deal with.

Not all students expressed shifts in awareness of illness. Student 6F gave brief acknowledgement of patient experience, but her response to Journal Task 3 is couched

within the discourse of the BPSM. Even her recognition of illness experience is hedged (line 55 *Italics added*), although lines 58-63 show a clearer appreciation. This example reflects very well Cornish's (2004) critique of the original BPSM as an aggregative, dualistic model dominated by biomedicine (above 2.2.2.3). Note that lines 64 — 70 appear to reflect a different 'challenge' to that noted in line 63 (in which the 'challenge' is experienced by the patient) – in lines 64 following the challenge is to the pharmacist, and not the person living with RA and any therapeutic regimen:

- 54 1. *My understanding has changed* in that I not only understand what the
 55 disease is about, *I also understand somewhat how a patient diagnosed with*
 56 *RA feels*. I've also learnt that early detection and adequate treatment of this
 57 disease is essential.
- 58 2. Living with RA would mean a change in lifestyle, sometimes even
 59 limiting oneself from things that they could previously do but now can't,
 60 and also limiting oneself in terms of the places they can go. This would be
 61 quite frustrating. Also, being someone who enjoys her independence,
 62 depending on someone will be quite difficult. In addition, living with pain,
 63 and taking chronic medication would be quite a challenge.
- 64 I think the challenge would be in ensuring the patient would tolerate the
 65 side-effects of the medication for long enough so that the medication will
 66 start taking effect. Also, with older patients, helping them remember to
 67 take the medication would be quite a challenge. An individualised
 68 pharmaceutical care plan would be a great help in this regard. I also think
 69 that the patience and understanding of the patient's family and of his/her
 70 pharmacist is quite essential.

Student responses to Journal Task 4 (Thinking about the NEXT session in the light of what Dr ***** discussed with you today - what questions would you like Dr ** to specifically address in her lecture? What DRPs can you imagine with regimens for RA? Why would these problems occur?) focussed primarily on the first question and are therefore quite issue specific (the lecturer was to address the pharmacology of the drugs commonly used in treatment of RA). However responses that were given to the second part – perhaps unsurprisingly given expectations – are firmly within the *Biomedical/Compliance* discourse (even if elements may arguably fit the BPSM, they nonetheless serve to underline Cornish's critique). Student 1A's response acknowledges the side-effects (line 72), and the complexity of treatment regimens (lines 73-74), and gives some acknowledgement of illness experience (lines 79-82), but the prime focus of these comments is the overtly biomedical 'non-compliance of the patient':

- 71 Non- compliance is a huge drug-related problem, I think, with these
 72 patients. Patients are not compliant for various reasons, apart from side

73 effects. Often taking medication for these patients is seen as a task and a
74 negotiation. It becomes monotonous and patients, kind of like feel, “do I
75 really have to take my medicine today?” Also, since the therapeutic effects
76 of chronic medication only comes into effect at least 6 weeks into
77 treatment, this is also another factor that discourages compliance. Also in
78 the case of Arthritis, getting treatment results in slowing down the
79 progression of the disease, it does not cure it, most patients are aware of
80 this, and this in some patients can discourage compliance, as they feel that
81 they are still going to suffer from the nasty stages of the disease eventually
82 anyway (Student 1A).

Student 5A’s response, while showing some indication of illness awareness (lines 85-86), continues to reflect the primary DRPs as ‘compliance’ problems, and reflects the biomedical discourse of the BPSM:

83 Obviously each drug has its own set of side effects which the patient may
84 experience and this could also add to compliance problems,as well as what
85 kind of benefit the patient sees the treatment having. do the pros outway
86 the cons of the medication in their mind.

Similar compliance-focussed concerns are evident in Student 6F’s response: ‘The NSAID’s cause alot of GIT⁹ problems, which in turn can lead to non-compliance. Also, with especially with the elderly, forgetting to take their medication can pose a DRP’.

Student 7K’s response shows a significantly more nuanced perspective. Student 7K initially recognised the primary DRPs as inherent in the side effects of the drugs and of incorrect prescription (practitioner and/or medicine related effects), but later the same day returned to the Journal to add a balance relating to patient medicine practice – but still linked to drug side-effects. Lines 94-98 were coded *Shift/Troubling certainty*, because although the student begins by framing this as a compliance problem (line 94), this is rendered reasonable by the ‘severe pain’ (lines 95-96), and the patient’s response to side effects (lines 97-98). Despite this shift, the overall response remains dominated by the BPSM discourse of *biomedical/compliance*:

87 DRP's could be the use of the wrong drug, such as the steroids instead of a
88 disease modifying drug.
89 Also the use of NSAIDS when analgesics would work for pain,
90 minimising the GIT effects.
91 Non- compliance could be a huge problem due to medication that doesn't
92 seem to be working.
93 9/03 (Further comment)

⁹ GIT: Gastro-intestinal tract

94 They could also not comply, by perhaps taking too many or more likely
95 too often their anti-inflammatories and analgesics because of their severe
96 pain, by also not sticking with their drug regime by not taking the correct
97 dose of their disease modifying agents too, taking too few or at less
98 intervals because of their side effects.

Student 3C once again reflects a greater openness to patient perspectives (Illness and BPSP). Student 3C's response is lengthy and proposes a detailed outline of the wide range of side-effects of the medications most commonly used in the treatment of RA. The following extract (from the much longer response), extends beyond the discourse of the biomedical model by acknowledging other approaches to healthcare, and that people living with chronic illness increasingly make choices outside of the biomedical realm, although the text ends with a comment aligned with biomedical discourse (lines 103 – 104 *Italics added*). This text was coded *Shift/Troubling certainty* (lines 99 – 103) and *Professional-Expert* (lines 103-104):

99 I am quite interested in hearing approaches toward complementary
100 medicine and Dr ** readily agreed that it was best to allow the patients to
101 decide on their regimen while adhering to their chronic medication- but are
102 there not side effects or possible problems with the use of these drugs
103 together? I have experienced many patients who *resort to complementary*
104 *medication before seeking professional help.*

In the students' reflections on the process and experience of drawing up the Pharmaceutical Care Plan¹⁰ used by the Pharmacy Faculty as part of their development of pharmaceutical care practice (Appendix 'B'), some of the students expressed discomfort at the experience of a theory/practice gap:

105 I think the most difficult part in drawing up the pharmaceutical care plan
106 was with regards to the interventions. On my pharmaceutical care plan I
107 stated that I would intervene by monitoring the patients treatment, check
108 on the patients adherence and compliance with regards to her medicine
109 taking, as well as deal with actual and potential drug-related problems.
110 The difficulty arose in how to go about carrying out these interventions,
111 for example, how do I know that the patient is compliant or adherent, how
112 can I help the patient be compliant or adherent, how do I intervene and
113 monitor? When do I intervene? (Student 1A).

¹⁰ The task questions were: 1. What was the most difficult part of drawing up this care plan? 2. How would you describe the patient's attitude toward her medication? Explain as best you can what you feel motivates her attitude and what could be done to support or improve her understanding of her illness and her medicine taking behaviour.

The elision of adherence/compliance noted above (5.1.3) is evident, suggesting that the biomedical model continues to dominate in attempts to be ‘patient centred’ (lines 108, 111-112). The entire extract reflects the aggregated BPSM, dominated by a practitioner-centred approach and characterised by the language of surveillance and (attempts at) control. While this passage could have been multiple coded (*Biomedical; Patient-expert; Biomedical/compliance*), I coded the passage *Shift/Troubling certainty*, as it reflects the student’s recognition of the inadequacy of the biomedical compliance discourse, and even of her professional role. The initial certainty to which Student 1A admits (lines 106-109), gives way to the reality of structural constraints, including those related to the patient’s exercise of agency (lines 109 – 113). What made this uncertainty clearer was that in the preceding paragraph, the student notes: ‘the patient was knowledgeable about her condition and medication and understood the importance of compliance and adherence to therapy’. Once the surveillance role of the pharmacist was removed by the patient’s own agency (the student notes that it is the patient’s experience and personal knowledge that informs her medicine practice - ‘this patient had seen [a family member]¹¹ suffer from rheumatoid arthritis she knew about the treatment and what she could expect from the illness’ and ‘This patient knew that the medication was helping her and she felt that it was important to take her medication, because she was petrified of the final outcome if the RA was left uncontrolled.’), the student was unsure of her professional role. The reductive biomedical discourse of professionalism does not permit a relationship-centred role in which the patient’s agency can be viewed as enabling a covenantal relationship: either the pharmacist’s role is redundant (the patient is compliant) or reduced to surveillance.

Other students reflect the same sense of loss of purpose in the face of patient agency. Student 2L’s response notes role uncertainty and a recognition of the patient’s knowledge and medicine practice, which precipitates this uncertainty (the extract below was coded *Shift/Troubling certainty* and *Shift/Patient knowledge* – lines 116-118 – but as with the previous text, substantially reflects a biomedical discourse of pharmacy practice):

114 *I found the most difficult part of this assignment was to find an area where*
 115 *we could benefit her as she is compliant with all her medications and has a*
 116 *very good understanding of her disease and her medicine taking. at*
 117 *present my patient is very aware of her disease and how to manage it*
 118 *effectively. she has extensive knowledge regarding her medication and is*
 119 *aware that without it her disease would be a lot worse.*

¹¹ Removed to safeguard confidentiality.

Student 3C noted ‘how difficult it is for a pharmacist or doctor to attempt to understand a problem as presented by a patient, when one has little knowledge on the exact compliancy and will have to make assumptions regarding with which drug the problem may lie’. This extract (coded *Shift/Troubling certainty*, but as with others, reflecting the *Biomedical /compliance* discourse underpinning the BPSM), reflects the inadequacy of any approach to understanding ‘patient’ medicine practice that is focussed on practitioner agency. Here the ‘patient’ (without agency) ‘presents a problem’: despite the lack of agency, the problem – a difficulty for the HCP – is constructed as the responsibility of the patient. Once again, a relationship-centred approach would serve to recognise where the agency lies (or is shared), and facilitate positive engagement between HCP and the person seeking professional advice.

Another dimension of uncertainty as to the pharmacist’s role, based on the biomedical / compliance discourse, is evidenced when Student 3C notes (in a later and somewhat convoluted section of her response to Journal Task 5 – Italics added):

120 These factors are all understandings the patient has regarding her chronic
121 illness situation, and does not appear to do her own research into the
122 illness or the treatments. This situation leads one to believe that maybe in
123 this instance, *as she is happy in her medication regimen, perhaps does not*
124 *require further readings or articles on the various different treatments to*
125 *be provided but necessarily ONLY* regarding her current medication and
126 use thereof, along with interests dealing with her own care of her body.

Illustrating the over-emphasis on ‘educating’ the patient (the patient in this instance was a retired school teacher), the pharmacist is at a loss as to what role is left once the product is being employed correctly (or so it seems), and the patient has no apparent requirement of ‘education’. Once again, the biomedical reductive approach (be it practitioner / product or patient-centred), does not permit the on-going professional relationship inherent in a relationship-centred approach such as the BPSP / Concordance approach, linked to Evetts’ (2003 and also above 6.2.2 & 6.2.3) understanding of professionalism as supporting patients in their risk-decisions – which in chronic illness are ongoing.

One student’s response to Journal Task 5 reflected a recognition of the role of the pharmacist in supporting a person living with chronic illness, through a relationship-centred approach. Student 4L (a mature-age student who has a number of years of experience as a pharmacy assistant in rural communities in an African country), noted:

127 The background knowledge the patient have, makes it (RA) a feareble
 128 disease, this may bring about positive and negative effects.May lead to
 129 improved compliance, as the patient tries to avoid what she had seen or
 130 was told, also to live a better life. The odd part is that with such drug
 131 interactions and complications of the disease the patient hope fates away
 132 with time. The patient should be encouraged to talk more freely about the
 133 disease, this could lead to change of perception,that fear can be
 134 overcomed. Fear related physiological changes such as stress and anxiety
 135 could be well stabilised.Openness can help her share information about her
 136 daily feeling with the family and friends and this will lead to assistance
 137 when ever necessary, and reminding her of her medication, the disease will
 138 be depersonalised.

The student's use of English makes some aspects of this passage difficult ('the disease will be depersonalized' in lines 137-138 seems to imply a biomedical discourse, and yet in its wider context, it would appear it could mean something she does not need to bear alone). That said the student recognises the patient's knowledge (line 127), acknowledges the supercomplexity of living with chronic illness and related medication regimens (lines 128 – 132), and goes on to present a relationship-centred role for the pharmacist (lines 132-138). Despite the single reference to 'compliance' (line 129) I coded this passage *BPSP* and *Concordance* as I believe it presents a thorough-going commitment to supporting and advising the person living with RA, recognising the agency (and structural enablements and constraints) involved in chronic illness. The pharmacist acknowledges the patient's knowing, her medicine practice and her illness experience.

Despite this last extract, I would argue that the students' Journal texts considered above suggest that the *discourse predominant in student texts prior to, and including, the first interview with the patients*, is the discourse of the biopsychosocial model (BPSM) underpinned by biomedical/compliance and professional-expert discourses on healthcare practice. This would appear to be in accordance with the underlying discourse of the model of pharmaceutical care presented in the course documentation for PAP in the Bachelor of Pharmacy offered by the Rhodes University Faculty of Pharmacy.

In response to the heuristic categories proposed by Johnstone (2002 and above, Table 8-ii), the student texts considered above reflect a discourse that is constrained by the dualistic categories of the biomedical approach (body/mind; expert/lay; compliance/non-compliance).

The predominant ideological position adopted in the texts is that of the professional-expert over against the passive layperson, although some students found this a difficult position to maintain and began to use the discourse of illness. Although only once (Student 3C, lines 99 – 104, above) was there some indication of a discourse that is subversive of the biomedical discourse. The students' confusion as to the role of the pharmacist in the face of patients exercising their agency with respect to medicine practice and displaying clear illness-related knowledge, is some indication of Johnstone's second heuristic statement: discourse and the limitations of language. Students found that their 'grammars' were being aligned with those of the patients: a form of 'challenge' by the patients, and acquiescence by the students (Johnstone 2002:228 and Table 8-ii (b) above). Related to this, and with respect to the third heuristic statement, students began by positioning themselves as professional-experts over against lay patients (responses to Journal Task 1 especially), but following the interviews found themselves acknowledging the status of their patient's knowing and experience (lines 115 – 126). There was substantial evidence of 'discourse and intertextuality' (heuristic statement four Table 8-ii (d) above) throughout the texts, and this was noted explicitly above. Some students did reflect difficulty with the media (heuristic statement five), finding the PCPs limiting and restrictive, especially student 4A who noted in her response to Journal task 5:

139 The format of the patient care plan that we used was confusing. We use the
140 same one on our CEP pracs and i battled to understand how to complete it
141 then. I think that was what made it so difficult. Its hard to think of all the
142 little things we should cover in our care plans but i think practise makes
143 perfect. I would do mine very differently now.

This was the only occasion in which any student expressed concern at the media possibilities restricting their expression.

Despite the overwhelming predominance of biomedical / BPSM discourse, there is some evidence to suggest that the discursive practices of some students (1A, 3C, 2L, 4L and perhaps 7K) have undergone some 'troubling' of assumptions, and that for these students there appears to be a growing sense of awareness of patient agency, and the value of attending to illness discourse.

8.4.2 What discourse is predominant in student texts representing the reflection on the course at its completion?

The primary texts which I shall use to consider a response to this question are the Reflective Statements that made up the final component (chronologically) in their assessment

portfolios, and comments in the course evaluation. While it is possible to attribute texts to specific students with respect to the Reflective Statements, the evaluation was anonymous, and this will limit the usefulness of the evaluation in indicating shifts in the discourse of specific students. Despite this, it remains a useful indicator for my response to the overall question which framed the analysis of the texts: *Is there evidence that the (brief) participation in the discourse community of chronic illness, supported by the experiential learning of the Elective, granted students access to the discourse of illness?*

8.4.2.1 What about the film?

I have used the viewing of the film as the marker for the end of the part of the elective during which students were exposed to what was familiar material (biomedical and pharmaceutical considerations of RA and discussions about patient interviewing and the completion of the Pharmaceutical Care Plans). During this section of the course students were not exposed to sociological perspectives, discourse, or the interrogation of epistemological assumptions. The viewing of the film was used to bring about the transition from the familiar to the critical, and to do so by using a medium which facilitates holistic involvement (7.3.1 above). The choice of ‘Wit’ (Nicholls 1998) was made in order to confront the students, having spent time with their patients, with an almost visceral experience of the asymmetry of power evident in discourses of expert verses lay, professional versus patient, healer versus sick (Cohen 2000). The initial critique of assumptions could then be done using the ‘safe’ characters and practices represented in the film, before turning the focus onto pharmacy. The Journal reflections were specific to the film, and were part of the process of assisting the students in engaging with their own experiences of the film. As these Journals contain no identifying information they are included as ‘Appendix ‘I’’. The Journal Task 6 asked the following questions:

1. How different from / similar to each other, were Prof Bearing, Prof Kelekian and Dr Posner at the beginning of the film? In what ways did these differences / similarities change as the film progressed?
2. How would you describe the VALUES, ATTITUDES and COMMUNICATION of the medical professionals exemplified in the film?
3. Looking especially at the diagnosis announcement and the medical interview and examination undertaken by Jason Posner, how would you describe the VALUES, ATTITUDES and COMMUNICATION which occurred in these examples?
4. Comparing the above (3) with the incident between Susie and Vivian involving the popsicle - what ATTITUDES, VALUES and COMMUNICATION were displayed here?

In a review of 'Wit' for the *Lancet*, Bregman (1999) muses on his experience on viewing a stage version: 'And we are left, along with the chilling awareness of how bondage to pure intellect can desiccate a life, with a more redemptive vision of intelligence coexisting with tenderness and love' – which captures in both discourse and sentiment the challenge which was intended by viewing the film at this point in the course. The focus on values and attitudes was a deliberate introduction of the need for an affective element in a relationship-centred approach to pharmaceutical care.

Student 1A's use of descriptors with respect to the values and attitudes displayed by the medical practitioners is consistent: 'Dr Posner' is 'distant, uncomfortable, quick, displayed no eye contact', 'did not care about the patient or did not even begin to try to understand what the patient was going through'. 'Dr Kelekian' 'was non-emotional. He used scientific language to explain Vivian's diagnosis to her which she did not understand and he did not realise that she did not understand what he was saying'. These attitudes and values (which the Student links to behaviour and actions) are contrasted with those of the nurse 'Susie': 'empathy and care'; 'Susie respects her [the patient's] choice and more importantly understands it'; 'She was very different, she displayed empathy towards the patient, she was caring and understanding. She checked on Vivian, was there for Vivian when she needed someone and was concerned about her treatment'.

The other students reflect a similar construction of the values and attitudes of the three representatives of the healthcare profession, with Student 2L suggesting: 'This film shows that the medical practitioners regarded [sic] their patients as objects or a disease and not as individual people. There is a distinct lack in communication between the doctors and their patients as they do not feel it necessary to develop any kind of relationship with them.' Student 3C reflects: 'They derive their value from an understanding and appreciation of the disease entity. The nurse (Sister Susie), however, attempts to improve the quality of life of the person suffering. The value she places on medical situations is that quality of human life is more important than quantity; per se. Suzie values the dignity of human life and attempts to offer this to her patients, regardless of their illness.' And as a final example, Student 7K noted: 'The medical professionals in this film convey, that they value their research work more than the patients they treat, they do not value caring relationships and taking an interest in how their patient is really doing. Their communication is one way and in their terms and expressions, they do not really listen and so do not really communicate

interpersonally, but through tests, and results. They lack genuine concern for their patient's well being.' (All Journal responses in Appendix 'I').

It is important to note that the students also realised that the 'patient' ('Professor Vivian Bearing') in this film was, in the beginning, little different from the medical practitioners in attitude, and in so being participated in her own de-humanization. Student 7K's comment is representative:

Prof. Bearing and Prof Kelekian were quite similar in the beginning with regards to their dedication to their work and not their patient/student, as you see in the opening scene and when Vivian refers back to her teaching.

At the end they are very much different, Prof Kelekian still has no relationship with his patient and only sees her as a research project, whereas Vivian has realised the importance of relationships especially caring ones.

There is thus no specific allusion to their own practice in these reflections. There is however, a very clear indication of the characteristics and the values and attitudes they would expect to underpin a healthcare professional's practice: Student 1A: empathy; respect for the patient's choices; understanding. Student 2L: values the dignity of human life; - all comments which refer to the professional care portrayed by the nurse. The students are equally damning of the attitudes and values they would *not* value in a healthcare professional: Student 1A: distant; failure to try to understand the patient's perspective; failure to communicate. Student 2L agrees, and adds condemnation of the treatment of patients as objects, and the failure to establish relationships with their patients. Within the prized and rejected values and attitudes, lies the affective description of what needs to be 'known' for a relationship-centred approach to healthcare. What remains to be seen is how that was evidenced in the texts which represented the students' reflection on their learning through the module.

8.4.2.2 The last words

The final Journal task involved the students' responses to the questions:

- 1.) What would you suggest are the major assumptions which underlie the 'concordance' model?
- 2.) What social circumstances are different in South Africa to those at work in the UK that may impact on a concordance model?
- 3) What main (practical) problems would you foresee in following a concordance model?

Most Journal responses do not retain the discourse of compassion and empathy noted in the reflections on ‘Wit’, but rather are laced with a dose of biomedical distance such as: ‘Level of education plays a big role in determining whether a patient is concordant or not’ (Student 1A). Aside from the meaninglessness of the concept of ‘a concordant patient’ (5.1.4 above), the location of a substantial part of the problem in the need for an educated patient is essentially a biomedical response. At the same time there is recognition of the complexity of communication involved in healthcare, but the student does not seem to grant space for the HCP to be lacking in education with regard to language skills, cultural sensitivity and awareness, or communicative skills. Students 3C, 6F and 7K generally support these views, adding lack of infrastructure, restricted availability of medications, inadequate staffing and lack of incentive for HCP support for a time-intensive approach. Student 6F briefly acknowledges that innovative approaches should be considered, including the suggestion that HCPs be required to learn additional languages at some level.

The views of Student 4L, however, are in stark contrast to those of the other students:

144 The main problem that I foresee in following concordance is 'time
145 constrainment', level of education and understanding of the Health
146 professionals. The latter is of major importance because unless a health
147 professional understand the background of the patient, it is usually hard to
148 identify social contrubuting factors towards non adherence. This also have
149 cultural effect, to be acceptable in any society one need to evaluate and
150 understand the cultural believes, and be able to relate to the scientific
151 knowledge that one posses, this can affect patient-health professional
152 relationship, especially where in certain cultures other things are not
153 acceptable [sic].

This student’s perspective offers a challenging corrective to the tendency to locate the problem in the patient. The student does acknowledge infrastructural constraints and low numbers of pharmacists especially in rural areas, but these are system problems. The student locates the ‘main problem’ squarely in the ability (and readiness) of the pharmacist to meet the needs of the patient. Once again this student argues for a relationship-centred approach to pharmaceutical care.

The Reflection Statements from the final assessment portfolios formed, in effect, the students’ summation of their learning experience. The task description required: ‘A minimum of a 600 (maximum 1200) word reflection on the process of interviewing a patient and drawing up the PCP, noting any learning which the student deems significant’

(Appendix 'D', Course Documentation, Para. 6). The full text of the Reflection Statements can be found in Appendix 'G'.

Student 1A's text reflects the predominance of the biomedical BPSM discourse sustained throughout this student's Journal responses. While there is some acknowledgement of patient knowledge and agency, this is not integrated into a relationship-centred approach. We are told that 'the patient was knowledgeable to a certain extent about her condition and medication and *understood the importance of compliance and adherence to therapy*' (Italics added). Despite earlier expressing concern at the difficulty of 'intervening' to 'solve' problems (lines 105 – 113, above), the student, while re-affirming the difficulty, goes on to say: 'I learnt from doing the PCP plan the importance of coming up with interventions during drug-therapy, because if we as pharmacists don't intervene we are effectively doing nothing for the patient or for the health of the general public'. The pharmacist is construed as the professional who must 'come up with interventions', and the values and attitudes of partnership and empathy are lost. Despite affirming the relevance of concordance, the student sums up the learning from this experience as:

154 I learnt the importance of having full knowledge about all the drugs in a
155 complex regimen, because the side effects and drug interactions have the
156 potential to cause adverse reactions in a patient if these are not fully
157 investigated or at least seen as potential drug-related problems. The PCP
158 plan also taught me to be thorough in my research and recognize all
159 aspects of patient care, from constructing drug regimens, to monitoring
160 and intervening.

'All aspects of patient care' however, do not seem to extend beyond biomedical control. There is little evidence that this student has gained substantial access to the discourse of illness, nor has shifted toward a relationship-centred perspective of pharmaceutical care required for concordance to be effective.

Student 2L's Reflection begins:

161 In my four years of pharmacy I have had very limited contact with actual
162 patients. Our brains are saturated with the theory, but once the textbooks
163 are closed the real world proves to be a very different place. In the same
164 way that we have discussed how our patient's medicine taking behavior is
165 affected by what they have experienced, our knowledge of living with a
166 chronic illness means nothing until we have experienced it or at least are
167 able to view it through someone else's understanding of their experience.

There is immediately some indication of awareness of patient experience as 'knowing' that is valuable in medicine-taking decisions. There is also acknowledgement of the pharmacist's

knowledge to be qualitatively different and insufficient on its own in the process of reaching medicine practice decisions (lines 164-167). The student points toward the importance of a relationship-centred approach to working with patients, noting:

168 The interviewing process was especially valuable to me because like so many other
169 pharmacy and medical students, I am not a peoples persons and learning the skills
170 of building a relationship with a patient is very important to me.

This commitment is further evidenced in the student's comment (used as a prefacing quotation to this chapter);

171 The theoretical knowledge she has of her disease put us to shame and we
172 were able to gain so much from listening to her physical, but more
173 importantly her emotional journey. I think it is important for health
174 professionals to be able to read between the lines. Even though our
175 questions as pharmacists are very clinical, the way a person answers each
176 different question, the language they use, the look on their faces can tell so
177 much about what they have been through and where they are emotionally
178 at the time of the interview.

Here the student clearly acknowledges the patient's knowledge, the need to be aware of the whole person, the importance of language as not simply unproblematic representation, and the importance of the role of emotion in communication in healthcare. The student ends the Reflection statement:

179 Letting a patient tell you their whole story can be surprisingly valuable to
180 us with regards to ensuring drug adherence and I think pharmacists miss
181 many important details because what they think are the right, important
182 questions are actually the least valuable. One of the most important things
183 I learnt from this elective was that it is important to have constant
184 interaction with your patients so that you can build a relationship where
185 each party respects the other. I feel that this is essential to the pharmacist
186 patient relationship.

Despite the reference to 'ensuring drug adherence' in describing the achievement of optimal medicine practice, the discourse of a relationship-centred approach to pharmaceutical care is predominant in this text, and the student shows awareness of the importance of the patient's experience of RA (illness discourse).

Student 3C's Reflection is complicated by occasionally idiosyncratic language use, making analysis difficult at times: 'It is through such an interview that we are reminded of the necessity of a pharmacist to listen to, and indulge in an empathetic attitude toward the patient in their disease state.' It appears unlikely that the student means 'indulge' in the literal sense ('to yield to a desire; to pamper' Collins English Dictionary 1979), and it may thus be safe to suggest that the student recognizes the importance of empathy for, and

understanding of, the patient's experience. This interpretation is supported by the student's concluding paragraph:

187 The interview process and drawing up the pharmaceutical care plan has
188 developed in me a better understanding regarding chronic illness and the
189 medicine taking behaviour of such a patient. Developing the adherence
190 management plan in potential concordance with the patient, and
191 researching into the best adherence aids, emphasized the importance of a
192 partnership in the health care of the patient. It is important to encourage a
193 responsibility toward their medication regimen, of which requires
194 counseling and information. The above methods along with a more 'multi-
195 disciplinary' approach from all health care workers involved, including
196 stress management and relaxation techniques for instance, will offer the
197 patient a more holistic approach to their chronic illness. This will
198 ultimately encourage adherence and management of the illness, and avoid
199 unnecessary adverse drug reactions.

Although once again, there is reference to 'adherence' (line 189-90 and again 195) and 'management of the illness' (line 198), the concern is directed at drug complications (ADRs) which are properly the concern of the pharmacist's expertise. There is also a focus on mutual responsibility within a relationship-centred, holistic approach (lines 187 – 194). Although there are elements of the biomedical BPSM, I would argue that a relationship-centred, concordance-based discourse predominates.

Student 4L's response presented a problem of assessment at the time of submission, and now presents a problem of analysis for this study. This student is a speaker of English as an alternative language, and is a foreign student. This may have in part contributed to the student submitting a Reflection on the wrong aspect of the course – rheumatoid arthritis rather than the experience of interviewing a patient and considering a pharmacist response. In some ways this renders this text inappropriate for inclusion in the study. With the text and analysis bracketed by that caveat, the following remains useful:

200 The complications of the disease may also lead to different lifestyle
201 modifications, this is not an easy thing for a person to achieve, but through
202 good communication skill and negotiations patients are empowered to
203 participate in decision making to wards their respective health and body.
204 Patients can not be forced to take their medication but can be encouraged
205 to do so. Patient education about the disease and the consequences of not
206 taking treatment should be put forward and benefits and disadvantages of
207 not adhering to the treatment and modification of other habits.

208

209 In all chronic medication it is important to take into account the
210 background, culture and religious beliefs of the patient. The patient
211 perception, beliefs and social influences towards rheumatoid arthritis (RA)

212 are very important in helping the doctor or pharmacist to identify the
213 necessary approach and to enable proper communication. However good
214 communication skills are necessary to help the patient express his/her
215 views. It is important to determine patient understanding of the disease.
216 The importance of medication and medication taking behavior and
217 compliance can only be picked through best communication methods.

The student's difficulty with English appears to have led to a slightly misleading opening sentence (line 200) which seems to suggest that the 'disease' will lead to a therapeutic lifestyle change. While it may be that the student meant that the pain, loss of mobility and further consequences of inflammation of membranes throughout the body would force change, I would suggest the student was referring to healthcare proposals in the light of RA. From line 202 on (with the possible exception of lines 212-214) the discourse is consistent with this student's previous Journal response (Journal 7 – 8.4.1 above), and proposes a relationship-centred approach to healthcare that is wholly compatible with the BPSP (2.2.2.3 above), concordance (5.1.4) and the understanding of pharmaceutical care proposed above (6.2.3). While the reference to 'compliance' (line 217) may suggest that this is an example of Heath (2003), Jones (2003), and Armstrong's (2005) doubting critique of concordance as a 'Wolf in sheep's clothing' (Heath 2003 – above 5.1.4), the student's consistent concern for the dignity and understanding of the patient suggests otherwise. It is interesting that, and why, he construes the role of the...

218 pharmacist role as drug counselor is very important. Because of the nature
219 of the disease and drugs used, it very important to make sure that proper
220 communication is achieved or the patient life maybe endangered. This
221 means the health professionals should make sure that together with the
222 patient they eliminate the stigma behind the disease, so that patient can
223 openly discuss the condition and be able to seek professional advice at any
224 time any thing happens. It is important to ensure that the patient knows her
225 medication well, and what s/he can avoid or not use concurrently with RA
226 medication.

Such a role and practice-focus honours the expertise of the pharmacist and the need of the patient in a way which maintains dignity and facilitates a therapeutic relationship. This is consistently maintained and emphasised in a way that meets all the criteria for concordance (see italicised text in lines 227– 239 and cf. 5.1.4 above):

227 Patient need to be *educated about their disease and medication, however*
228 *this should be broad, so that the patient perceptions and beliefs are taken*
229 *in to account. It is important to find what patients think about their disease*
230 *status, with respect to their cultural, social and religious beliefs. This can*
231 *help to reach a compromise as to what medication to be given, since some*
232 *people do not want to be considered sick.*

233 *For concordance to exist, doctors and pharmacist need to develop respect*
234 *for their patient's beliefs and wishes. They should also appreciate the*
235 *background, experiences and preferences of the patient. All the health*
236 *professionals for the benefit of the patient and for the optimum outcomes*
237 *should work as a team, however proper diagnosis both from disease based*
238 *and drug related problems are very important to win the confidence of the*
239 *patient.*

The predominant biomedical discourse in Student 4L's first Journal response ('[Pharmacists]...should monitor patient compliance and maintain good relationship with their patients' (8.4.1 above)) gives way in the response to Journal 7 and the final Reflection, to the student's access to illness discourse. It is important to note that this is not a silencing of biomedicine, but rather the acknowledgement of the priority of another discourse in the relationship-centred encounter between pharmacist and the person seeking support. The recognition of illness discourse is fundamental to the praxis of the BPSP and concordance perspectives.

Student 5A's Reflection was difficult to place. Superficially, this student appears to have grasped the substance of the discourses underlying concordance and relationship-centeredness. There are however, indications of the kind of approach noted by Heath (2003), Jones (2003), and Armstrong (2004): 'Concordance is fast becoming the acceptable face of compliance: the goals remain the same but the technique is more subtle as patients are recruited to direct themselves in medicine-taking' (Armstrong 2004:26). In the extract below the emphasis appears to be on 'getting the patient' to make a number of prior commitments to a relationship with the pharmacist. This seems to reflect a misunderstanding of 'relationship-centred'. Trust cannot be achieved through contrivance, and lines 240-245 present a practitioner-centred approach cloaked in the guise of patient focus.

240 I think a big part of building the desired relationship with a patient is
241 getting them to trust you and to simply like you and the way you treat
242 them. This to me is the most difficult part of a concordant relationship
243 because every person's personality is so different and in my opinion we as
244 health professionals will have to adapt our approaches accordingly if we
245 want to bring in concordance successfully.

The degree of respect for the patient's dignity and autonomy central to a relationship-centred approach is disturbingly missing from the following extract:

246 She [the patient] also showed a great amount of respect for us and seemed
247 almost honored to have us interview her. I have seen this kind of attitude
248 during interviews with patients in the township. It seems that patients who
249 feel they are very much less educated or of a lower class have this sort of
250 attitude towards health professionals. These patients are fairly easy to

251 work with face to face, however they still may not adhere to their drug
252 regimen at home when you are not there to motivate them everyday.

Lines 246-250 reflect an ideological position of social superiority, and set up a 'them' and 'us' positioning inappropriate to concordance. This sense of unease is reinforced in lines 250-252 in which a person is categorized into a 'sort', and a 'sort' who cannot be trusted at that. The thin veneer of illness discourse does not disguise the underlying acceptance of asymmetry of power which the BPSM would find uncomfortable. This paternalism runs as a thread throughout the text (*Italics added*). The Student notes with approval the patient's apparent fear of experiencing the more common symptoms of RA (deformity of her hands and severe, chronic, pain). The text needs little comment:

253 This "Fear" takes on a very important role in drug adherence and even
254 though we don't want to give our patients a negative attitude it may be the
255 only way to build adherence. *I think it is very important to visually show*
256 *patients what could happen to them if they do not adhere to their*
257 *treatment.* Unfortunately, for some patients that fear is not a reality for
258 themselves and they continue to live in denial until they experience it
259 themselves, and then, it is probably too late.

The closing paragraph of the reflection leaves no doubt as to the nature of the relationship between pharmacist and patient expected:

260 I must say I was hoping for a patient with a more challenging personality,
261 but of course even for Mrs. M it doesn't just end there. Her attitude may
262 change with time and again it is the health professionals job to pick it up
263 and find ways to make sure it doesn't and just because she was a pleasure
264 to work with and seemed the model patient there are always little potential
265 problems that we are trained to watch out for and must be careful not to
266 forget this.

Despite a superficial use of the signs of patient-centred discourse, the authority of biomedicine will pick up Mrs M's attitude change 'and find ways to make sure it doesn't [change]'. Patient autonomy is discarded; patient agency is treated as something to be guarded against and prevented. As Armstrong states '...let us not get starry-eyed about concordance. The main goal of many (most?) of its proponents is to get patients to take their medicines as directed, or at least not waste them' (2005:26). Here, clearly articulated is Heath's (2003) 'wolf in a sheep's clothing'.

Student 6F began the course firmly rooted in a biomedical perspective ('The role of the pharmacist is to ensure that the patient is adherent with regard to their medicine-taking behaviour, and also to counsel and be supportive to the patient' - response to Journal 1), and showed a consistent BPSM approach. Even the opening paragraph of her Reflection reflects

her discomfort about a relationship-based approach (*Italics added*): ‘The process of interviewing a patient was, for me, quite daunting at first. However, it has *provided me with certain tools necessary for an effective and efficient interaction with patients.*’ Relationships with patients are characterised as ‘interactions’ – isolated and distanced – and hedged about with effectiveness and efficiency – the language of biomedicine.

While lacking the paternalism evident in Student 5A’s text, Student 6F also appears to reflect an instrumental approach of ‘using the tools’ to good effect:

267 Asking open-ended questions helped to elicit a more patient-centred focus
268 as opposed to closed-ended questions. But when time is short, direct
269 questions may be the only way to do business. However, direct questions
270 often do not help us understand things from a customer's point of view and
271 they rarely give the impression of caring (even when we do passionately
272 care).⁶ The questions provided served as a good guideline, however, some
273 deviations were necessary. For instance, the order of the questions needed
274 to be altered. I also found that letting the patient speak her mind provided
275 some valuable information.

While the language of the text reflects a drawing on text-book language (for example the footnote reference in line 272), the student does appear to have recognised that the PCP was flawed in its design and that a slavish use of the itemised questions served to silence the person with whom the pharmacist was speaking (lines 272-275).

The tussle between the student’s biomedical perspective and the encounter with a new (illness / relationship-centred discourse) is illustrated throughout the reflection:

276 Being open-minded when interviewing patients, as well as not letting one's
277 bias influence the drawing up of the most effective pharmaceutical care
278 plan, are both essential. In addition, I realised that one should deconstruct
279 one's own assumptions in order to comprehend the patients' assumptions.²
280 It was also important to take into account when drawing up the care plan
281 that it is the patients' agendas and not that of the health care professional's
282 that determine whether patients take medicines.

An underlying call for ‘objectivity’ (lines 276-278) competes with a new awareness – still at the level of reference-able academic discourse (footnote in line 279) – of the need to interrogate one's own assumptions. The ‘most effective’ pharmaceutical care plan (line 277) finds itself at odds with the recognition of the patient’s agency in medicine practice (lines 281-282).

The student does show evidence of access to illness discourse, and developing awareness of what a patient-centred / concordance approach to pharmaceutical care would involve. The student notes that they have

283 learnt that the ability to manage symptoms associated with a chronic
284 condition has enormous implications for living with a semblance of
285 normalcy in a patient's life. In addition, a variety of factors affect decision-
286 making in the context of chronic conditions.

In another passage Student 6F is the only student to recognise

287 ...the gendered aspects of domestic life and their impact on coping with
288 illness, given that other research has shown that women often put the
289 health and well-being of others before that of themselves. Kate*, a nursing
290 sister at [****], does her own housework, and she also experiences early
291 morning stiffness due to her rheumatoid arthritis. This is an example of
292 how gendered aspects impact on coping with illness.

Student 6F's text's reflect a gradual recognition of the need to extend beyond the reductive biomedical approach, although it would be placing too much credence on the formal recognition granted in the Reflection, to suggest that the student has access to illness discourse. I would argue however, that Student 6F does provide evidence of recognising that the patient's experience is valuable, and that granting the patient space in therapeutic decision-making is appropriate – although at this stage, it may simply be that this is efficient and effective, rather than the moral imperative suggested by Thomasama (1983) and Borrell-Carrió *et al* (2004).

Student 7K's texts have reflected the BPSM, underpinned by an essential biomedical discourse. The Reflection statement begins accordingly:

293 It is our job as pharmacists to ensure that our patients are receiving the full
294 therapeutic benefit of their medication to help us to help the patient we
295 need to conduct a thorough interview on the patient with regard to the
296 above mentioned, in order to compile a pharmaceutical care plan. This
297 care plan helps us identify any drug related problems the patient may have
298 at present or be at risk of developing.

Although this discourse remains dominant, there is evidence of an awareness of the need to admit and understand the patient's knowing through experience (lines 299-307):

299 In the beginning it was awkward but as the situation relaxed we felt free to
300 modify our questions to her situation, to try to understand her point of
301 view, beliefs and reasons for her behaviour. It was also important to try
302 read between the lines, analyse the way she answered particular questions,

303 what her body language communicated, the information she told us and the
304 information she did not tell us. It was important to take note of how she
305 described her relationships with her family and friends, especially with
306 those members of her family who also have RA. To take note of how she
307 spoke about the disease and what relationship she had with it.

One significant observation is the importance of ‘how she spoke about the disease and what relationship she had with it’ (lines 306-7) – reflecting excellent insight as to the way chronic illness becomes integrated into the life narrative of the person (Frank 1995). The student reflects a shift away from biomedical empiricism, despite the fall-back into ‘compliance’:

308 It was interesting that with a seemingly very compliant patient drug related
309 problems especially interactions still manifested. Thus it was clearly seen
310 how important it is to really take time in interviewing patients to gather all
311 the information you can and then take action in drawing up a
312 pharmaceutical care plan properly to identify drug related problems and
313 take measures to try correct them.

Despite this recognition of the patient’s *concerns*, there is still no recognition of the patient’s *agenda*, and the student seems surprised that ‘with a seemingly very compliant patient drug related problems especially interactions still manifested’ (lines 308-309). The closing paragraph from Student 7K’s Reflection illustrates the fundamental discourse of a biomedical / BPSM perspective, even if this paragraph does begin with a brief recognition of illness discourse – it does so in a way that maintains the objectification of the patient as ‘them’ and ‘their lives’.

314 It helped take our focus off just the clinical pharmacology and onto the
315 patient and how their disease and medication affects them and their lives.
316 It also highlighted how important our job of isolating drug related
317 problems and correcting them really is. It would be great for all patients to
318 realize the seriousness of their diseases and be so knowledgeable on their
319 medication and life style modifications.

While there is no doubt that the core of the pharmacist’s expertise is the application of pharmaceutical and pharmacological knowledge to drug-related concerns, the relegation of the patient’s role to ‘realizing the seriousness of their disease’ ironically fails to recognise the knowledge and experience of the person whose health concern is at issue. In sum, Student 7K shows some evidence of understanding of the experience of people living with chronic illness, but does not show access to illness discourse and the resultant implications of this discourse for knowing in the therapeutic relationship, or for patient agency in medicine practice.

In the **course evaluation** the students were asked to respond (anonymously) to three questions (Appendix 'H'):

- 1.) What have you learned through your participation in this course? If any of this was a new insight, please indicate this.
- 2.) The Faculty has asked whether the course will be offered again in 2005 – what would your response be (please give reasons).
- 3.) If the course were offered again what would you like to see (please give reasons where appropriate):
 - a. Kept as it is;
 - b. Changed;
 - c. Stopped;

As the evaluations were anonymous it is not possible to compare these responses to earlier comments by students. Of the twelve students only seven responded, but it is not possible to assume that these are the same seven who participated in the research project. The analysis thus gives simply another perspective on students' discursive practices regarding healthcare. The evaluation also gives some idea how the students experienced the course as a teaching and learning experience. My analysis will focus on responses to question 1 which are recorded below (*What have you learned through your participation in this course? If any of this was a new insight, please indicate this*):

320 New insights into chronic illness, compliance. Learnt about the new terms
321 of adherence and concordance. Learnt in depth about Rheumatoid Arthritis
322 and gained insight into what it is like to live with this disease. Learnt that
323 words have connotations, i.e. one cannot take them at face value. This was
324 definitely a new insight.

Learning 'about terms' is somewhat ambiguous and clearly does not indicate any epistemological access to the discourse communities to which they refer, but this student's comment does reflect some awareness of illness discourse, and indeed of discourse itself. The latter (coded *Shift/Troubling certainty*) reflects recognition of the inappropriateness of applying biomedical epistemological perspectives uncritically in the social context.

325 I have learnt the implications of a chronic disease to a patient. I have learnt
326 that pharmacists have an important role to play in a chronic patient, and
327 what this role is. I have learnt not to take what a patient says at face value,
328 but rather to dig deeper.

The problematic grammar of this text makes interpretation difficult (line 325), but too much cannot be drawn with respect to the student's access to illness discourse as lines 327-328 do not necessarily suggest the need to pay attention to the patient's accounts. They could just as well suggest that patients cannot be trusted to provide reliable information.

329 This course was extremely valuable. It gave me a great understanding
330 about chronic illness and chronic patients. I got better insight into how to
331 deal with chronic patients and how to manage them. I got a great
332 understanding of concordance, compliance and adherence which was very
333 valuable. Interviewing an actual patient, with a chronic illness was great. It
334 was very good experience and I learnt a lot from this. Also very interesting
335 and enjoyable.

Despite this student's assertion that the course was 'extremely valuable', lines 327-330 reflect the language of biomedicine ('dealing' with and 'managing them'). Asymmetry of power appears unproblematic, and so I have some uncertainty about the student's assertion of 'concordance, compliance and adherence'.

336 Most importantly, I learnt how to distinguish between what we as health
337 care givers may perceive an illness to be, vs. how a patient may experience
338 this illness. This difference emphasized the need for concordance in
339 establishing a health care regimen for a patient, to attempt to influence
340 adherence. The course incorporated all forms of chronic illness, not just
341 Rheumatoid Arthritis, but I did feel that I am now more aware and
342 knowledgeable regarding RA drugs, their indications and side effects. Not
343 only did we focus on the use of language and empathy in conversation
344 with the patient, we established that words used — within their context or
345 intent — may be interpreted differently by another, and the impact this has
346 on the mind, attitude and opinions.

This student's response contrasts significantly from the previous student's comments. Lines 333- 335, suggest that this student has engaged with the illness discourse. There is some indication that this student has not only *learnt* something about the discourse (acquired some 'meta-level knowing'), but has begun, however peripherally, to *acquire* (performance through exposure to) knowledge of the discourse (Gee 1990:146). Lines 342-344 provide further evidence of engagement with illness discourse, although line 339 appears to reflect the concerns expressed by Armstrong (2004) regarding the pragmatic use of any means to ensure obedient patients. It is possible that this student's engagement with illness discourse, both as a result of learning and acquisition (Gee 1990, and above 3.1.4), is beginning to use illness discourse to resist biomedical discourse.

347 How concordance works; comparison between concordance, adherence
348 and compliance, gave me deep insight on how to improve patient quality
349 of life. Conducting interview on real patient, gives the opportunity to
350 experience what one can expect as a pharmacist in real life. How to present
351 reports and to discuss the findings.

Once again, this student does not really reflect engagement with the discourses. Line 349 suggests that HCP agency is still regarded as dominant.

352 I have learnt to take the whole person into account when designing
353 pharmaceutical care plans. Also learnt about meanings of "words" to
354 patients.

While this text (lines 352 – 354) does reflect some engagement with illness discourse, the text retains the dominance of HCP agency found in the biomedical discourse which underpins the BPSM.

The following text explicitly reflects recognition of the asymmetry of power between an HCP and a patient, and acknowledges that this can impact on quality of health care:

355 That chronic illness is so far very different to any other illness, it needs a
356 different approach and complete participation of the patient. There is
357 disparity between understanding between the health professional and
358 patients. To achieve common understanding there should be compromises
359 from both parties.

This student's response does show access to illness discourse and an understanding of the concept of concordance. The student recognizes the ideological issues at stake in HCP/patient relationships.

8.4.3 Discussion of analysis

The texts considered in 8.4.1 generally reflected the biopsychosocial model of health care, allied to the discourse of biomedicine (2.2.2.3 above). Such an approach aims at being patient centred, but retains the focus on practitioner agency, while attempting to recognise the context of the sick person. Students tended to categorize people living with chronic illness as 'patients' (but without in any way signalling this as a problematic labelling), and frequently used distancing pronouns such as 'they' and 'them' and possessive such as 'their'. Such discursive practice distances the 'pharmacist' from the 'patient'. Three of the students (Students 2L, 3C, & 4L) showed recognition of the ideology that informs these categorizations. Students 3C and 4L in particular made use of illness discourse, and the sociological critique of biomedicine, to resist the biomedical discourse framing of the professional relationship between pharmacist and the sick person. Student 4L in particular moved to a strong assertion of the need for a context-related, holistic and ideologically sensitive approach to pharmaceutical care, which overtly challenged the assumption of the passive patient. This student's engagement with illness discourse could well be rooted in his prior experience as a pharmacist technician in the rural areas of a neighbouring African

country which permitted him to resist that biomedical discourse predominant in the Faculty. One student in particular used the signs and symbols of illness discourse, but subverted this discourse with the clear intention of using a relationship to ensure compliance.

The students generally responded with insight and thoughtfulness to the Journal reflection on the film 'Wit' (8.4.2.1 above). They identified the asymmetry of power present in the HCP/patient interactions (including nurses, doctors, and medical technicians), the way patients are construed as passive recipients, and the way caring knowledge and practice are ridiculed by the characters representing biomedicine in the film. Students' responses reflect affective engagement with the film and the issues raised by the film. However, there was not a great deal of evidence in the available texts that all of the students in the study carried this engagement across into the consideration of their own practice, in that none specifically relate reflections on the film to their practice. That said, a number of students do identify the importance for healthcare practice of the relationship between HCP and patients. The final extract from the evaluation (8.4.2.1: lines 355 – 359) makes explicit reference to asymmetry of power between HCP and patients, and that this may impact on healthcare practice. Student 2L (8.4.2.1: 161 – 167; 168 - 170) provides evidence of reflexivity in recognizing her own tendency to adopt a distancing approach, locating this in her personality as someone who 'is not a people's person'. Despite this recognition of her own discomfort with working with people, Student 2L emphasises the importance of a caring relationship between herself as a pharmacist, and patients with whom she has to work. The student also recognizes the problematic nature of the objective, clinical distancing, inherent in the pharmaceutical care plan process to which they had been exposed in their training (8.4.2.2: 174 – 178).

One incident occurred that appears to reflect the impact of the film, although it took place outside this study. A group of fourth-year students, some of whom had been on the course, were accompanying a Faculty staff member and hospital staff on rounds in the local hospital. While observing a patient and considering the case report in the patient's presence, the patient died. This was traumatic for the students. As a result of this incident, a group of students approached the pharmaceuticals professor who had been an observer in the course, and requested the opportunity for all involved in the hospital rounds to see 'Wit' as they felt that the way the film engaged with the issues of values, attitudes and care – particularly with respect to terminally ill people – would be helpful. The students did see the film, and –

based on anecdotal evidence – many found it helpful. The issue here is that the film had engaged the students on the course at a deep enough level for them to see it as way of supporting in, and confronting their peers with, the realities of patient-care.

The one aspect of the course which students really did find valuable was the interaction with patients. This accords with the arguments presented in 7.2 and 7.3 above about the importance of experiential learning. Based on the Journal comments it was this experience more than any other, which challenged assumptions and broadened their understanding of both disease and illness. For at least Students 2L, 3C, 4L and 6F, the patient interviews and resultant process of considering the pharmaceutical care process in the light of exposure to the disease/illness debate, and with the support of their colleagues in group sessions, proved to be important. It was this process which seems directly to have led to more questioning of their assumptions than any other – although a number of students mention the heuristic experience of the insights of discourse theory in their evaluation comments. This combination reflects Gee’s comments that discourses can only be accessed¹² through acquisition, not learning, although learning can facilitate meta-level knowledge (1990). Gee does accept that acquisition may occur through learning experiences, ‘but only...because of a process of apprenticeship and social practice’ (1990:147).

Student evaluation comments, while not uncritical, were unanimous that the course should be continued as part of the normal curriculum of the Bachelor of Pharmacy degree (Appendix ‘H’, Item 2), and at least one student valued the course running concurrent with the Community Experience Practical (see 8.1.1 above):

Yes, I do agree that this course should be offered again. *I felt it was very interesting and very humbling - to stop regarding ourselves as future pharmacists as having power and control over the health of the public.* I believe this course offers a new perspective as to the role of pharmacists, especially in the case of patients suffering from chronic illness, of which we can deliver into the old, traditional role. This course, I believe, runs concurrently with our Pharm Admin and Practice course -especially pertaining to the Community Experience Programme. *It offers valid and valuable experiences and perspectives of which we have not touched upon within the fields of this degree* (Student evaluation comment. Italics added)

¹² Gee uses ‘mastered’ (1990:146), but mastering of a discourse was never a goal or possibility under the circumstances of this course. At best I hoped for access that raised awareness.

The results of this analysis are no more than illustrative of the experience of a small group of students. They do, however, suggest that the pedagogic principles proposed above (7.3) are practical within a crowded curriculum, and that students appear to benefit from the teaching and learning experience. Four of the seven students who participated in the study evidenced a shift in their access to illness discourse. With this shift in access to an alternative discourse, these students appear to have developed a new awareness of patient care, and pharmaceutical care built around a patient-centred model. Students' awareness of the complexity of medicine regimens was brought home forcefully, and students were exposed to knowledgeable patients who exercised their agency in healthcare decisions.

The closing words on the analysis of this illustrative course are those of a student's response to the evaluation;

It should be offered next year if possible. This course emphasizes what we have been learning in theory. It is more of reality than theory. ... By the end of the course, I have something to be proud of. It is a wonderful course.

Chapter 9: Conclusion

What is required ... is not a replacement of existing orientations but their displacement within a multivocality that recognizes the respective legitimacies of various claims and finds ways to balance these claims, making each aware of the others. In a multivocal medical world, non-medical voices would be heard (Frank 1995:147).

9.1 Introduction

I began this study with five assumptions based on my own experiences as someone who is a member of the ‘remission society’ (Frank 1995):

1. that in the biomedical process of diagnosis and treatment of chronic disease, the voice of the person living with the disorder is silenced;
2. this results in people living with chronic illness developing an ambivalent dependence on / resistance to, response toward healthcare practitioners and toward recommended therapeutic regimens;
3. that the part of the therapeutic regimen most marked by ‘patient’ resistance to biomedicine is medicine-taking practice, which remains highly problematic to all concerned; and
4. that the failure of pharmacists to apply their particular expertise places both pharmacy as a profession, and the people living with chronic illness at risk.

The fifth assumption – also based on my own experiences – was that these are unnecessary and avoidable.

Although the first three assumptions related to the healthcare profession in general, the fourth assumption provided the lens through which the first three were considered. The focus on pharmacy, as I noted in the introductory chapter, arose from my own context, both as a person using a range of high-risk medicines and as a curriculum consultant working alongside a university pharmacy faculty (1.1 above). This combination of circumstances led me to question what at first appeared to be the epistemological assumptions that underpinned the preparation of pharmacy students to interact with patients. Inevitably, questions about epistemology required the framing of analytically

prior questions about ontology (Bhaskar 1979; 2002; Byrne 2002), human agency and social structure (Bhaskar 1979; Archer 1995; 2000; 2002; 2003). It was through this interrogation of the philosophical assumptions that appeared to underpin the course documentation to which I was exposed in the curriculum work, that I became aware of the biomedical hegemony in the pharmacy curriculum (Turner 1987; 2.2.1 above; Traulsen & Bissell 2004; 6.1.1 above). This hegemony has unintended consequences as it undermines some of the very professional values of being 'patient centred' (SAPC 2004) to which the pharmacy profession aspires. For as Kleinman forcefully puts it:

The biomedical system replaces...[the]..."soft," therefore devalued, psychosocial concern with meanings with the scientifically "hard," therefore overvalued, technical quest for the control of symptoms. This pernicious value transformation is a serious failing of modern medicine: it disables the healer and disembowels the chronically ill (Kleinman 1988:10).

9.2 Formative perspectives

With this critique in mind, and in consideration of the first of my five assumptions (although this impacts on all five), this study has referred to the critique of positivist/empiricist philosophical underpinnings of biomedicine, and proposes critical realism as a more satisfactory philosophical underlabourer for healthcare practice (Bhaskar 1979; Sayer 1992; 2000; Williams, S 2000a; 2.2.1 – 2.3 above). Central to critical realism's critique has been the epistemic fallacy present in positivist/empiricist biomedical perspectives in which ontology and epistemology are collapsed into one another permitting too easily the assumption that the empirical exhausts the real, or at least anything of interest in the real (Bhaskar 1979).

9.2.1 Ontological

The long-running critique of the 'biomedical model' has been framed largely by the presentation of a social constructionist, hermeneutic, paradigmatic alternative (Annandale 1998; Playle & Keeley 1998; Woodward & Watt 2000; 2.2 above). This perspective too, is subject to the criticism of succumbing to the epistemic fallacy; in this case placing the referent beyond knowing and leaving us with a sign suspended in relativism (Bhaskar 1979; Sayer 1992; 2000; Archer 1995). George Engel's 'Bio-psychosocial Model' (BPSM), which has arisen to challenge the biomedical model with regard to healthcare practice, emerged from the social constructionist perspective (S. Williams 2000a; Borrell-Carrió *et al.* 2004; Cornish 2004). The BPSM reflects the philosophical problematic highlighted by Bhaskar's criticism of social constructionism (1979; 2002) in that it

implicitly retains some of the very ontological assumptions of empiricism, namely a reductive dualism which leaves the person who is ill as merely the inarticulate symptom-bearing site of a disease entity (Marks 2000; Cornish 2004; 2.2.2.3 above).

Against the background of these criticisms, I have supported Simon Williams' argument (S.Williams 2000a) that critical realism¹ provides a more congruent philosophical basis for healthcare practice (2.3 above). Critical realism (Bhaskar 1978; 1979; 2002; Sayer 2000 and 2.3 above) reminds us that we have to do with causal tendencies, and not constant conjunctions of events. Reality is stratified into the *transient* and the *intransient*. The former consists of the *empirical* and the *actual*. Beneath/behind the empirical lies the actual, accessible through practice. There is:

...a primacy of practice in conceptualising our experience.... Contra empiricism, experience is not passively imprinted on the senses by nature as if on a blank page.... We are thrown into the real world and make what we can of situations, of which we have no prior understanding, through exercising our species endowments in praxis (Archer 2000:127).

The empirical is emergent from the actual, which itself is emergent from the *real*, which is *intransient*. The 'real' is understood as 'whatever exists, be it natural or social, regardless of whether it is an empirical object for us, and whether we happen to have an adequate understanding of its nature' (Sayer 2000:11). The real also includes the causal structures and powers proper to existing objects. These causal powers are the 'capacities to behave in particular ways' which may be exercised or unexercised (as 'causal liabilities or passive powers') (Sayer 2000:11).

The usefulness of critical realism as a philosophical underlabourer (Bhaskar 1979; 2002) for healthcare is that, unlike empiricism, it reminds us that the world – and especially in the case of human persons and social reality – does not operate in the closed system of a scientific experiment, but is always an open system. Algorithms need to be applied with caution and evidence is not without interpretation (because knowledge is geo-historical and value-laden): simply put, in diagnostic and therapeutic decisions it is not scientifically legitimate to conflate the person experiencing an illness with the empirical 'evidence' of signs and symptoms. Such conflation will continue to lead healthcare practice to 'disable the healer and disembowel the chronically ill' (Kleinman 1988:10).

¹ Although as noted above (2.3.2 & 2.3.3) 'critical realism' is Bhaskar's term, and is largely a philosophical perspective, while 'social realism' is Archer's and is sociological, philosophically social realism is rooted in a critical realist ontology. To enhance readability I shall use 'critical realism' to refer to both in this chapter.

9.2.2 Epistemological

As was clear in the consideration of critical realism (2.3), knowledge is the result of human praxis, and is thus *transitive* and socially constructed. As noted above (2.3.5, n.6) social construction of knowledge is not to be confused with the social ‘construction’ of the reality to which such knowledge refers: ‘For the most part, social scientists are cast in the modest role of *construing* rather than ‘constructing’ the social world’ (Sayer 2000:11 Italics added). Sayer’s distinction cautions against the epistemic fallacy inherent in social constructionism in which ways of knowing the world (construing the world) are conflated with the way the world is, leading to the idea that we ‘construct’ reality (or realities). As the distinction between the two words suggests, *construing* is heuristic, related to understanding, making meaning, while *constructing* (reality), is inherently reductive in its meaning and suggestive of building a reality. Note that in this distinction *constructing knowledge*, is thus different from constructing a / the world, for at best we can offer a construal of the latter.

I have argued for a sociocultural epistemological perspective based on the work of Wells (1999 & 3.1 above), as this is congruent with the ontological and sociological perspectives of critical and social realism respectively. Such a sociocultural epistemology recognizes the emergent, geo-historical, practice-based, transitive nature of knowing (3.2 above). Such a perspective recognises that knowing is formed through the integration into our experience of the practice of those who have gone before and, in that sense, is cumulative (as opposed to knowledge as unproblematically additive) (Wells 1999; 3.1.3 & Table 3-ii above). Socio-cultural epistemology leads to:

Understanding...[as]...holistic, intuitive and not necessarily made explicit, deeply involved in action, understanding creates possibilities for and constrains our actions – ‘constitutes the interpretive framework in terms of which we make sense of new experience’ and guides action (Table 3-ii above).

Such an epistemological perspective coupled with a critical realist ontology and social realist understanding of human agency, could facilitate the ‘displacement’ (but not replacement – Frank 1995 & above) of the way in which ‘The biomedical system replaces...[the]...“soft,” therefore devalued, psychosocial concern with meanings with the scientifically “hard,” therefore overvalued, technical quest for the control of symptoms’ (Kleinman 1988:10).

9.2.3 Discourse

A sociocultural epistemological perspective recognises the role of discourse in knowing (Wells 1999; 3.1.4 above). As indicated above (3.1.4) I adopted Kress's understanding of 'discourse' as:

...systematically-organised sets of statements which give expression to the meanings and values of an institution [or community]. [Discourses]... define, describe and delimit what it is possible to say (and by extension – what is possible to do or not to do) with respect to the area of concern of that institution [or community] whether marginally or centrally. A discourse provides a set of possible statements about a given area and organises and gives structure to that manner in which a particular topic, object, process is to be talked about. In that it provides descriptions, rules, permissions and prohibitions of social and individual actions (Kress 1989:7).

Under such an understanding it becomes apparent that the dominance of pharmacy practice ('those activities of pharmacists that most closely and directly impact on or interact with the final consumer of medicines, be they patients or users' – Wingfield, Bissell & Anderson 2004:2384) by an empiricist biomedical discourse excludes the discourse of experience, feelings, values and individuality, which constitutes the discourse of illness (4.3 & 4.3.3 above). So in the *act of pharmacy* (2.2 above), biomedical disease discourse with a concern for treating an entity identified through empirical tests, signs and symptoms, excludes the patient's illness by delimiting 'what it is possible to say (and by extension – what it is possible to do)'. Such a dominance is ideological ('an exercise of power through the manufacture of consent to or at least acquiescence towards' the uncritical use of language – Fairclough 1989:4) and can thus be resisted through access to another discourse (Fairclough 1989; Gee 1990).

Before considering the possibility of access to the discourse of another discourse community, it was necessary to illustrate how the competing discourses at work in healthcare reveal themselves in practice. This was done through a consideration of three focus areas directly related to pharmacy practice:

- health, disease, illness and sickness;
- medicine-taking practice, and
- pharmacy and pharmacy education.

9.2.4 Patient experience and healthcare perceptions

In considering the second and third of my five starting assumptions, I began with examining how disease and illness could be understood. The debate around disease, illness

and sickness (conducted largely in the fields of sociology and critical health psychology) reflects the outworking of the competing discourses in healthcare practice in general (4.3). One of the problems relating to biomedical discourse lies in its empiricist/positivist underpinnings and their conflation of ontology and epistemology: for here biomedical discourse does not simply *construe* the patient, it *constructs* them epistemologically in a ‘simplistic neo-Cartesian reduction of medicine to sciences of the mind, arithmetically added to science of the body and tied together with a ribbon of moral science’ (Pellegrino & Thomasama 1981:24 – above 2.2).

Further indication of the impact of the competing discourses was apparent in the brief consideration of the underlying debate around health itself, suggesting wider policy implications. In the discussion of chronic illness (4.4. above), I noted the rise of a discourse of resistance to the biomedical discourse of disease. This was well illustrated by Toombs (1996) and Charmaz (above 4.4):

[People managing their illness] become innovators. To do so they listen to their bodies and stay in tune with them in ways that they had not and in ways that Western culture discourages. They may make use of indigenous support groups, newsletters, and computer networks independent of professionals.... Some chronically ill people become so adept at monitoring and managing their illness that they break through textbook definitions, construct new ways of living with their illness; but medical professionals may not welcome their innovations... Consequently, ill people’s strategies for managing illness can require strategies for effective negotiations with professionals to minimize conflict (Charmaz 2000: 283 – 284).

The consequences of biomedical discourse for understanding therapeutic decisions (or in biomedical reduction – ‘behaviour’) by people living with illness, was considered in the discussion of ‘compliance and adherence’. In many cases biomedical discourse results in people being labelled as non-compliant or non-adherent and ‘constructed’ as deviant (5.1 & 5.2 above). The discourse of compliance potentially silences the knowing of the person who must live with illness, and denies the agency of the person whose decisions and actions will, in fact, determine medicine practice (5.1 above). Using the understanding of ‘discourse’ noted above, there is a sense in which ‘non-compliance’ may be better understood as resistance rather than deviance, as ‘patients’ choose to make their own decisions – informed by their own discourse communities of which medicine is one – something alluded to by Poss (2001) and Pound *et al.* (2005).

Something of a resistance of illness discourse was apparent in the concept of ‘adherence’, but resistance emerges most clearly in very recent – and as yet tenuous – moves toward a focus on the relationship between healthcare practitioners and people experiencing illness. This emerging discourse (relationship-centred or ‘concordance’ – 5.1.4 above) does not seek to replace the scientific knowledge and expertise of the healthcare professional, contrary to Prior’s (2003) dismissive arguments, but rather to extend the ‘shared conversations in epistemology’ (Harraway 1991 in Tong 1997:158) involved in therapeutic decisions.

Truth is *partial* in that no one individual or group possesses it entirely. Knowledge comes from facts and experiences, but since our facts and experiences are inevitably limited, our truths are never total. No one of us is ever objective enough because no one of us can ever see, hear, taste, smell, or touch enough. If we wish to secure a truth greater than our own, we must converse with people whose experiences are different than our own (Tong 1997:157).

9.2.5 Pharmacy

With respect to pharmacy and pharmacy education, the impact of discourses was framed by a socio-historical overview of pharmacy as a profession and the introduction of the concept of *pharmaceutical care* (6.2.3). Here, the fourth assumption with which I began the study, was considered in the light of the literature on pharmacy as a profession (6.2.1 – 6.2.2 above), and with reference to current changes surrounding healthcare in South Africa (6.1.2). The literature survey revealed a long-standing uncertainty within pharmacy, and self-interested opposition from within medicine, towards the idea of pharmacy as a profession. Gilbert (1998; 2001; 2004a; 2004b) locates this debate, including the ideological opposition from medicine, within the South African context (6.1.1 & 6.1.2 above).

Hepler (1987; Hepler & Strand 1990) argues that pharmacy’s desire for professional acceptance served to lead pharmacy as a profession into dominance by science. This argument is extended to propose that the way out of the resultant loss of purpose, was the adoption of the ‘philosophy’ of pharmaceutical care as the framework around which pharmacy should be developed (Hepler 1987; 6.1.1 & 6.2.3 above). However, before Hepler’s proposal could be evaluated as a response to my fourth assumption, and as a way of providing for my fifth assumption, it was necessary to consider the way professions have been understood during the period in which pharmacy evolved and defined itself as a profession. While the concepts of ‘profession’ and ‘professionalism’ are widely applied to a range of human socio-economic activities (Geisler 1994; Annandale 1998; Evetts 2003;

Traulsen & Bissell 2004), the focus of my consideration was on pharmacy. I argued that pharmacy retains an understanding of itself as a profession based on conceptions developed during the first half of the twentieth century (6.2.2 above):

...an occupation which is based on specialized intellectual study and training, the purpose of which is to supply skilled service or advice to others for a definite fee or salary (Carr-Saunders quoted in Denizin & Mettlin, 1968:375).

Such an understanding, while accepted by Hepler, is ill-suited to the notion of pharmaceutical care based on a 'covenantal relationship' as the governing principle of the pharmacy practice that is proposed by Hepler (1987).

Having sketched the trajectory of the debate around 'profession', I then argue that Evetts' proposed understanding of profession is better suited to pharmacy in a *risk society* (6.2.2 above, and Beck 2000 & 3.2 above). Evetts proposes that professions could be better understood as:

...structural, occupational and institutional arrangements for dealing with work associated with the uncertainties of modern lives in risk societies. Professionals are extensively engaged in dealing with risk, with risk assessment and, through the use of expert knowledge, enabling customers or clients [patients] to deal with uncertainty (Evetts 2003:397).

Such a conceptualization permits recognition of the expert knowledge which pharmacists do have, and recognizes the agency of the patient in making the final decisions and taking the decisive actions. This more easily facilitates a genuine covenantal relationship (involving the professional expertise of the pharmacist being recognised by the patient's act of granting trust in the pharmacist), than does the paternalism and objectivism inherent in the understanding of 'profession' noted by Carr-Saunders (6.2.2 – 6.2.3 above).

I then argued (6.2.3) for a revision of Hepler's original definition of pharmaceutical care as:

a covenantal relationship between a patient and a pharmacist in which the pharmacist performs drug use control functions (with appropriate knowledge and skill) governed by an awareness of and commitment to the patient's interest (1987:376).

This understanding remains product and practitioner centred and, despite an emphasis on 'the patient's interest' is rooted in a biomedical expert vs. lay paternalism. Following a sketch of the literature around the application of pharmaceutical care as a practice, and the critiques of professionalism offered by Geisler (1994) and Evetts (2003) and the proposals for an ethical basis for healthcare practice made by Thomasama (1983; 6.2.3 above), I proposed that pharmaceutical care be understood as the philosophy of practice:

...of a covenantal relationship between the pharmacist and a patient and, where relevant, caregivers and other healthcare practitioners, for the purpose of caring for that patient's drug-related needs. The goal of pharmaceutical care is the responsible provision of advice on, and drug-related therapy for the purpose of, achieving and sustaining an optimal improvement in a patient's health related quality of life (6.2.3 above).

The consideration of pharmaceutical care, and the resultant proposal of this understanding of pharmaceutical care forms the bridge between my fourth and fifth starting assumptions (that the failure of pharmacists to apply their particular expertise places both pharmacy as a profession, and the people living with chronic illness, at risk; that the first four assumptions reflect a situation that is unnecessary and avoidable).

9.3 Educational concerns

The call for changes in pharmacy education runs like a thread through the literature on pharmacy as a profession and pharmaceutical care as a philosophy of practice (Hepler 1987; Gray & Bodley Smit 1998; Das & Das 2001; Robinson 2003; Traulsen & Bissell 2004; above 6.1 & 6.2.4). My consideration of educational concerns relating to this study, and in response to my fifth starting assumption, began with a sketch of the pharmacy education landscape in South Africa, with specific reference to the Bachelor of Pharmacy (B.Pharm) offered in the Pharmacy Faculty at Rhodes University. I noted that the B.Pharm at Rhodes was heavily loaded with sciences (reflecting Hepler's concern - Hepler 1987), but had the real advantage of a course in Therapeutic Drug Monitoring (TDM) included in the Pharmacy Administration & Practice (PAP) course. While the underlying biopsychosocial and biomedical discourse(s) of PAP were analysed elsewhere (8.3 – 8.4), I then considered the calls by the International Pharmacy Federation (FIP 2000), Droege (2003), and Traulsen and Bissell (2004) for a shift in the focus of pharmacy education:

If practicing pharmaceutical care requires a shift in focus from drug product to patient, so does teaching future practitioners. The curriculum would have to address issues that go beyond didactic and experiential courses; it would also have to include environmental, cultural, and social components that can help to build a new conceptual framework of a professional practice (Droege 2003:72).

9.3.1 A supercomplex context and epistemological access

Following Barnett's (2000a & b) argument that we live in an age of supercomplexity (7.2.1 & 7.2.2), I argued that an approach to teaching and learning based on reductive dualisms was inadequate for healthcare professionals (7.2). In its place was needed an approach to

education which was concerned with the development of reflexivity (Archer 2000; 2002; 2003; above 2.3.4; 7.2 & 7.3) and would support pharmacists' epistemological access to the discourses of illness and medicine-taking practice (7.2.2 & 7.2.3). The understanding of discourse provided by Kress (1989, and above 3.1.4 & 9.2.3) and the concept of epistemological access (Jansen 2001; 7.2.3 above), provide a pedagogic link between the concerns expressed in the first four of my starting assumptions, and the fifth – that change is possible. Raising awareness of discourse provides one way of facilitating 'epistemological access': making people aware of the explicit and implicit rules, values and assumptions which are at work within different communities' ways of knowing. This could facilitate the pharmacy students' engagement with the discourse of illness not only by enabling their participation (however peripheral) in the discourse community of illness, but by raising awareness of the discourse(s) that underpin their community of practice.

In the discussion of discourse in 3.1.4 (above) I noted Gee's (1990) argument that discourse cannot be taught in a classroom, but can only be acquired through participation. With Gee's caveat in mind, and considering the concerns regarding the need for changes in pharmaceutical education (6.1; 6.2.4 & 9.3 above), I proposed an experiential approach to teaching and learning which included a deliberate focus on affective learning (7.3 above). I argued that a combination of patient interviews, the use of (selected) narrative film, an on-line reflective journal, critical considerations of theory, and a portfolio to assess student learning, could support not only student engagement with illness discourse, but facilitate reflexive praxis. This in turn could, I argue, facilitate pharmacy students' epistemological access to patient medicine-taking practice.

9.4 Summary and conclusion

In Chapter 8 I offered an examination of an illustrative course designed according to the proposals made in Chapter 7. The examination considers the course offered as a fourth year elective for the B. Pharm degree in the Rhodes Pharmacy faculty, and then considers whether the research question has been addressed. Using a critical approach to discourse analysis (Fairclough 1989; Johnstone 2002), I examined selected written texts produced by the students throughout the course. I considered the presence of the dominant discourse underpinning these texts at the beginning and end of the course, using the viewing of the film 'Wit' (Nicholls 1998) as the half-way point. I concluded that of the seven students who participated in the study, all evidenced a predominant biomedically informed BPSM discourse at the outset of the course. This reflects the discourse found in the course

documentation from their PAP course (Futter 1996; 2002a & b and above 8.4.1). Of the seven students, four – and possibly a fifth – displayed some resistance to the dominant discourse in some of their journals (8.4.1 above). At the end of the course the texts of three of the seven students reflected engagement with illness discourse in such a way as to problematize the dominance of the biomedically supported BPSM, and show some evidence of epistemological access to medicine-taking practice in chronic illness. One student in particular, whose pre-university experiences as a healthcare worker in rural areas of a neighbouring African country had presented him with invaluable exposure to patient experiences and the clash of biomedical and lay discourses of illness, showed significant evidence of epistemological access to medicine-taking practice in chronic illness.

As I have noted, Gee (1990 and 3.1.4 above) argues that acquisition of a discourse sufficient to become a member of a discourse community, is unlikely to be facilitated by classroom teaching, except perhaps if preceded by participation in that community. To Gee's caution must be added the recognition that the course under discussion, was a single 26 contact hour teaching and learning experience undertaken in the final year of a four year degree completely dominated by biomedical discourse. In view of this the results of the analysis of the students' documents are more positive than could perhaps have been expected. I believe that the results provide some indication that a course designed on the principles of experiential learning, with deliberate attention to affective learning, including the insights of social theory in order to make students aware of the presence of ideological discourse, has been useful. Such a course may present one way of responding to my final starting assumption: pharmacists committed to a professional practice based on pharmaceutical care may gain epistemological access to the medicine-taking practice of people living with chronic illness.

9.4.1 Limitations of the study and recommendations for further research

In the course evaluation (Appendix 'H') a number of students suggest that the course should be integrated into the mainstream PAP programme, and should occur earlier in their degree. The adoption of these suggestions would go some way to exposing students to an alternative discourse with which they could resist the dominance of biomedicine with regard to the act of pharmacy. Exposure of teaching staff in pharmacy faculties to the theoretical perspectives that have underpinned this study (critical realism and sociocultural epistemology) may also, over time, displace (not replace) biomedical dominance over the

discourse of pharmacist/patient interactions and medicine-taking practice among people with chronic illness. I believe that the contribution of this study may best lie in the linking of the insights from the sociological critique of biomedicine and the challenge of social realism to a sociocultural epistemology concerned for affective learning in order to inform a pedagogic approach to the education of pharmacy students.

I am cognisant that the course that provided an illustrative case study was localized to a volunteer group from one cohort of students from a single pharmacy Faculty. Such a small scale case study is clearly very far from generalizable. The purpose of the case study was to illustrate a possible teaching and learning intervention which could change the understanding of the act of pharmacy and serve to facilitate an improvement in the way pharmacy students understand medicine-taking practice. Further research will have to assess whether this model is practically viable among larger numbers and in other contexts, and whether the principles could be implemented to better effect earlier in the curriculum.

Appendix 'A'

Rhodes University Faculty of Pharmacy Student Handbook Entry (Curriculum)

http://www2.ru.ac.za/studentzone/future_students/studies/handbook2006.pdf

CURRICULUM

The Bachelor of Pharmacy curriculum is currently under revision and it is likely that a new curriculum will be introduced in 2006. In this event, entrance requirements and course descriptions may change.

The Bachelor of Pharmacy degree at Rhodes University is a 4 year programme. The curriculum for this degree is laid down by the South African Pharmacy Council and all students must pass all courses of this prescribed curriculum to be awarded the degree in Pharmacy. Whilst the general curriculum is prescribed, each of the universities that offer pharmacy have different emphases, thus making transfers between different Schools or Faculties of Pharmacy in South Africa difficult. At Rhodes University, candidates for the Bachelor of Pharmacy degree must complete a first year, taught by the cognate Science departments of the university. Students start the professional training towards their pharmacy degree at the commencement of their second year. In the final year students are permitted to select two electives or may undertake a research project in partial fulfilment of the requirements for the Bachelor of Pharmacy degree.

The specific subjects for each year of the Bachelor of Pharmacy degree and a description of the subjects are listed below:

BPharm 1	BPharm 2	BPharm 3	BPharm 4
Chemistry	Pharmaceutics 2	Pharmaceutics 3	Pharmaceutics 4
Mathematics	Anatomy and Physiology	Pharmaceutical Chemistry 3	Pharmaceutical Chemistry 4
Statistics	Pharmacy Administration and Practice 2	Pharmacy Administration and Practice 3	Pharmacy Administration and Practice 4
Physics	Pharmaceutical Chemistry 2	Pharmacology 3	Pharmacology 4
Computer Science	Pharmaceutical Biochemistry		Elective/Project **
Biology			
Introduction to Pharmacy			

** Elective courses may include topics such as Drug Regulation, Drug Information, Toxicology, Nutrition, Ageing, Managed Care Pharmacy and Pharmacoeconomics.

Anatomy and Physiology: A study of the functional anatomy and physiology of humans.

Pharmaceutical Biochemistry: A study of the important molecules found in living organisms.

Pharmaceutics: A three-year course covering basic pharmaceutical principles and their application to the formulation, production and assessment of medicinal products, microbiology and sterility.

Pharmaceutical Chemistry: A three-year course covering the study of the purity and chemical properties of various materials and formulations used in the practice of pharmacy.

Pharmacy Administration and Practice: A three-year programme, which examines management, legal and psychosocial principles and their application in providing safe and effective drug use by pharmacists and patients.

Pharmacology: A two-year study of the interactions between medicaments and cells or invaders of the human body; disease states and medicinal therapy used to relieve these; the toxic effects of household agents, medicines and street drugs.

ENTRY REQUIREMENTS

To gain acceptance into the Bachelor of Pharmacy programme an applicant must have passed the Matriculation Examination of the Joint Matriculation Board, or obtained an exemption certificate from the Board. In addition, the applicant must normally have obtained at least a D symbol in Mathematics on the Higher Grade and a D symbol in Physical Science and Biology on the Higher Grade.

Appendix 'B'

Rhodes University Faculty of Pharmacy

Pharmacy Administration and Practice IV

Pharmaceutical Care Plan¹ (2003 - 4)

Chronic Illness and medicine taking – Rheumatoid Arthritis Pharmaceutical Care Plan Interview

OBJECTIVES:

This practical provides you with the opportunity to interview a patient with diagnosed rheumatoid arthritis. The objectives of the interview are:

1. To learn to conduct a patient interview in order to collect patient, disease and pharmacotherapeutic data in order to assess and evaluate the patient's pharmacotherapy and develop a pharmaceutical care plan.
2. Become familiar with some of the factors influencing medicine-taking behaviour in patients living with Rheumatoid Arthritis.
3. To attempt to assess the patient's understanding of the nature of Rheumatoid Arthritis, and their perception of the threat of the disease to their quality of life.
4. To attempt to assess the patient's perception of the benefits of treatment.
5. To attempt to assess the patient's understanding of the importance of lifestyle and exercise responses to Rheumatoid Arthritis

BACKGROUND:

A patient's belief about their disease, its severity and its perceived threat has an important bearing on their health related behaviour and their agreement to work with a health care practitioner in a treatment regimen. Counselling and educating can however alter the patient's beliefs about the disease, and may improve medicine taking and other behaviour aimed at managing the illness. Pharmacists are in an excellent position to counsel, teach and support patient's behaviour. We do however need to understand the patient's perceptions and also the environmental factors, which may influence their preparedness and ability to manage their illness in cooperation with health care practitioners.

Pharmacists willing to practice pharmaceutical care, i.e. committed to preventing, resolving or alleviating patients' drug related problems and willing to accept shared responsibility for pharmacotherapeutic outcomes can play a major role in helping patients to manage their Rheumatoid Arthritis. (See attached copy of Browning 2001 for detail on RA).

¹ Please note that this document is based on the PCP used by students in the Community Education Practical which runs concurrent with the Chronic Illness elective. The only adaptations that have been made are related to the selected disorder.

TASK :

A group of patients have been selected from among those being treated by a local specialist physician for Rheumatoid Arthritis. You will have NO access to patient files or data. Your meeting with the patient will equate with that of a pharmacist meeting with a patient new to the primary health care setting (e.g. retail or private hospital pharmacy) in which you find yourself.

You will need to ensure that you are familiar with the disease state of Rheumatoid Arthritis by referring to the notes from Dr Jameson's lectures and to the attached paper by Browning.

You also need to familiarise yourself with the pharmaceutical care process you have followed in PAP IV.

You will visit a patient in a setting agreed to by yourself and the patient, and you will each interview one of the patients. The structured questionnaire will serve as a basis for the interview and for assessing the patient's understanding and experience of Rheumatoid Arthritis and the treatment she / he is receiving.

You are not expected to offer any advice or comment on treatment or the patient's experience.

You must obtain the patient's permission to record the interview on audiotape prior to the interview. Should the patient refuse such permission, request permission to record responses on the PCP form.

REPORT:

Your report for this practical will include a copy of the questionnaire i.e. the patient interview, and then you will be required to write a pharmaceutical care plan. This exercise will take you through the planning component of the comprehensive pharmaceutical care process. For the purposes of the practical you will not be fully implementing the plan

You will be expected to present a brief outline of your patient's experience of RA and identified or expected DRPs, plus a care plan at the TUESDAY, 23 March session. The report is to be handed in **BY 12:00, WEDNESDAY, 24 MARCH 2004.**

The report will NOT be assessed for marks at this stage, but will be read for and receive comments, returned to you at the beginning of next term, and form the basis for your portfolio submission which will require a formal Patient Care Plan based on your interview(s).

RHEUMATOID ARTHRITIS - PATIENT WORKUP OF DRUG THERAPY

Your name:

PATIENT DEMOGRAPHICS:

Patient name:

Date of Birth:
Mass:

Gender:

Height:

PATIENT BACKGROUND:

Family:

With whom do you live? (family /friends?)

Occupation:

Are you working?

Does your Rheumatoid Arthritis affect your ability to work in any way?

Does your medicine have any affect on your ability to work?

Lifestyle/Activity:

Does your Rheumatoid Arthritis affect your life in any way other way, is there anything that you are not able to do because of it, either at home or at work?

Medical Problem List (Diagnoses, complaints, conditions):

What illnesses do you presently have?

What illnesses have you had in the past?

Have you ever had an injury to a joint or bone?

Do you have any other aches or pains or complaints about your health?

History of present Illness/Medical History:

How long have you known that you have Rheumatoid Arthritis?

How did you feel before you started treatment? (What symptoms did the patient have eg: fatigue, pain, stiffness, loss of movement?)

How long have you taken medication for your Rheumatoid Arthritis?

Have you always been on this medication for Rheumatoid Arthritis since your original diagnosis, or has it changed? If changes have been made, what are these and why were they changed?

Understanding of disease state:

What do you understand about Rheumatoid Arthritis?

Have you any idea what might happen if you don't take the medicines prescribed by the doctor?

Current and past medication history:

What are all the medicines you are presently taking (prescription, OTC or traditional medicines), and how do you take them?

Do you feel that each of the medicines helps you?

Are there any bad effects when you take any of the medicines?

By doing a tablet count assess whether the patient appears to be compliant or not? (Type refers to: *prescription (Rx)*, *OTC*, *home remedies (HR)* or *traditional medicine (TM)* and Status is indicated by *active (A)* or *inactive (I)*.)

START-STOP DATES	DRUG PRODUCT	DOSE, ROUTE FREQUENCY	COMMENTS (EFFICACY, ADVERSE EFFECTS OR COMPLIANCE)	TYPE	STATUS

Understanding of drug therapy:

Do you feel better with the medicine than before you started the medicine?

What do you think this medicine is doing for you? (How is it helping?)

How do you store the medicines you use?

Concerns about drug therapy:

Is there anything that concerns or worries you about taking any of these medicines?

Expectations from drug therapy:

What are you hoping this medicine will do for you, how are you expecting to feel on this medicine? (Is the patient expecting a cure or a lessening of symptoms or an improved lifestyle?)

Other information affecting drug taking:

Do you have any problem taking this medicine as prescribed? (Eg is it difficult to take a dose at any particular time?)

Do you have any other problems which make it hard to take your medicines, eg an inability to swallow a tablet?

ALERTS:

Allergies and Adverse Reactions:

Have you ever had a bad reaction to any medicine in the past? If yes, can you remember what the medicine was and what happened?

Smoking/Alcohol/Recreational Drug Use:

Do you smoke, if so, how many cigarettes do you smoke a day?

Do you drink alcohol, if so, how often?

Compliance History:

Do you ever find it difficult to remember to take your medicines?

Is there anyone else who helps you to remember to take your medicines?

Since diagnosis, have you ever taken, or are you taking, any medicine which was not prescribed by your doctor or about which your doctor does not know? If so, what and why?

Family History:

Is there anyone else in your family who has or has had Rheumatoid Arthritis?

Other Special Alerts:

Do you know that what role exercise and rest should play in your management of Rheumatoid Arthritis?

Have you been able to change your diet and how easy have you found this to do?

[Is there anything else about the patient which should be a special alert? - Is the patient pregnant, appear to be malnourished (including obesity)?]

REVIEW OF SYSTEMS:

This needs to be asked as very general questions:

Do you have any other health problems?

Do you ever have trouble with your eyes, blurred vision?

Do you ever numbness, pain or burning in your feet or do you have any sores on your hands or feet?

Use the following as a summary of any answers to questions you have asked or any observations you have made.

SYSTEM/SYMPTOM	YES	NO	COMMENTS AND GENERAL OBSERVATIONS
APPEARANCE : unkempt, poor hygiene			
GENERAL : Fever, Fatigue, Weight Change, Pain			
PSYCHOLOGICAL STATUS : Nervousness, Sadness, insomnia, Hallucinations, Irritability, Tension, memory problems			
SKIN/HAIR/ NAILS : Skin colour, skin texture, Rashes, Dryness, Itching, excess hair, Hair loss, Dandruff, Nail bed			
HEAD/NEUROLOGICAL : Dizziness, Fainting, Headache, blackouts, seizures, tremors, spasms, stiffness, numbness, walking problems			
EYES : Redness, Poor eyesight, Pain, Blurring, Discharge, Glaucoma, Cataracts, Problems with contact lenses, Itchiness			
EARS : Hearing loss, Tinnitus, Earache, Discharge, Excessive wax			
NOSE/SINUSES : Colds, runny nose, hayfever, sinus problems, nose bleeds			
MOUTH/ PHARYNX : Sore throat, gum soreness/bleeding, dental problems, mouth ulcers, hoarseness, halitosis, unusual tastes			

NECK : Swollen glands, goitre, neck pain			
PULMONARY : Dyspnoea, wheezing, cough, asthma, bronchitis, emphysema, tuberculosis, haemoptysis			
CARDIOVASCULAR ; Chest pain, Hypertension, heart murmur, paroxysmal nocturnal dyspnoea, orthopnea, palpitations, orthostatic hypertension			
RENAL /URINARY : Polyuria, dysuria, urgency, nocturia, dribbling, incontinence, bleeding, urinary retention, stones,			
HEPATIC : jaundiced			
ABDOMEN : swallowing problems, heartburn, diarrhoea, constipation, nausea, vomiting, pain, vomiting blood, blood in stool, haemorrhoids, ascites, changes in bowel habits, flatulence, belching			
FEMALE REPRODUCTIVE : Vaginal discharge, itching, menstrual problems, venereal diseases, hot flushes, PMS MALE REPRODUCTIVE : Itching, discharge, sores, testicular pain/swelling, poor libido			
MUSCULOSKELETAL : Joint swelling, pain, deformities, redness, stiffness, weakness, limited movement, gout, backache, muscle cramps			
ENDOCRINE : thyroid problems, blood sugar problems, Addison's disease, Cushing's disease			

You will now use this interview as a basis for completing the rest of the pharmaceutical care planning process. You will also need to consult the literature for possible drug interactions, adverse effects etc.

Current Drug Therapy:				
Drug Name:	Dose, Strength, Route, Schedule	Duration Start Stop	Comments (efficacy, adverse effects or compliance)	Type (Rx/OTC/ Trad / Comp)
1. 2. 3. 4. 5. 6. 7. 8. 9. 10.				
Past Drug Therapy				
1. 2. 3. 4. 5.	6. 7. 8. 9. 10			
Expectations of Therapy:				
Dosing Schedule Time Line Circle actual administration times, and record appropriate meals above the line and medications below the line.				
Notes and other special alerts:				
Meals				
Medication				
IDENTIFICATION OF DRUG RELATED PROBLEMS				

ASSESSMENT	PROBLEM IDENTIFIED	ASSOCIATED DRUGS AND COMMENTS	RISK
INDICATION	UNNECESSARY DRUG THERAPY No medical indication Addiction/recreational use Non-drug therapy more appropriate Duplicate therapy Treating avoidable adverse reaction NEEDS ADDITIONAL THERAPY Untreated indication Synergistic/potentiating therapy Prophylactic/preventative therapy		Actual High risk At risk Possible No/low risk
EFFECTIVENESS	WRONG DRUG Dosage form inappropriate Contraindication present Condition refractory to drug Drug not indicated for condition More effective drug available DOSAGE TOO LOW Wrong dose Frequency/duration inappropriate Drug interaction Pharmacokinetic interaction Narrow therapeutic index		Actual High risk At risk Possible No/low risk

SAFETY	ADVERSE DRUG REACTION Not safest therapy Allergic reaction Incorrect administration Drug interaction Dosage change too rapid Undesired effect DOSAGE TOO HIGH Incorrect dose Frequency/duration inappropriate Drug interaction Pharmacokinetic interaction Narrow therapeutic index		Actual High risk At risk Possible No/low risk
COMPLIANCE	COMPLIANCE Drug product not available Cannot afford therapy Cannot swallow tolerate or admin drug Patient prefers not to take drug Does not understand instructions Drug/dosing regimen too complex Other reasons		Actual High risk At risk Possible No/low risk

STATEMENT OF DRUG RELATED PROBLEMS:

(Patient identifier, Problem/ Symptom, Problem Modifier, DRP type, Relationship to drug therapy)

1.

2.

3.

DESIRED GENERAL CLINICAL OUTCOMES: (GCO)

Cure the disease
 Eliminate/reduce symptoms
 Arrest/ slow progression of disease
 Prevent disease or symptoms
 Normalize physiological parameters

DESIRED PHARMACOTHERAPEUTIC OUTCOMES:

(State patient, progress and time factors, for each DRP)

POSSIBLE INTERVENTION ALTERNATIVES:

(State all possible therapeutic or non-therapeutic alternatives fully, for each DRP)

SELECT MOST APPROPRIATE INTERVENTION ALTERNATIVES AND STATE TAILORED REGIMEN:

(State the most appropriate therapeutic OR non-therapeutic alternative, stating drug, drug form, dose and tailored dosing regimen where appropriate)

List here all the additional information you would provide the patient with:

COUNSELLING INFORMATION CHECKLIST:**COUNSELLING INFORMATION**

Name of medication :

Indication for which medication is being given:

Route of administration:

Instructions for administration:
The dosage regimen, which should be carefully tailored to the patient's daily routine :
Time delay before an effect can be expected to be felt
What sort of beneficial effects can be expected from the medication:.
Major side effects of the medication, some idea of the likelihood of them occurring and when they can be expected to disappear:
Information on how to manage the side effects or what to do or who to contact if the side effects become unbearable:
Additional, more rare side effects should also be mentioned:
The length of treatment or how long the patient can reasonably be expected to be on the medication:
The number of times the medication needs to be repeated and at what time intervals.
Any precautions such as activities or food to avoid whilst on the medication or after treatment:
Any possible drug-drug or drug-disease interactions which could occur
Storage or ancillary instructions (eg store in a cool place):
What to do if a dose is missed.

MONITORING PLAN:	
POTENTIAL ADVERSE EFFECTS OF THERAPY:	
MONITORING PLAN: (What, who, how, frequency, when to start and stop, how to record)	
FOLLOW UP PLAN:	
DATE AND TIME OF FOLLOW UP:	WHO IS TO INITIATE FOLLOW UP AND HOW:

PHARMACIST'S INTERVENTIONS: Document date and nature of actual intervention and implementation of therapy	
DATE:	INTERVENTION:

Appendix 'C'

Taxonomy of Educational Objectives: The Affective Domain¹

Category	Illustrative usage
1. Receiving (Attending)	
a. Awareness	Develops awareness of aesthetic factors in objects; Develops awareness of colour, form and arrangement, and symbolic representations of people, things and situations;
b. Willingness to receive	Attends (Carefully) when others speak; Appreciation (tolerance) of cultural patterns exhibited by individuals from other groups; Increase in sensitivity to human need and pressing social problems;
c. Controlled or Selected Attention	Listens to music with some discrimination as to mood and meaning; Alertness to human values and judgements on life in literature;
2. Responding	
a. Acquiescence in responding	Willingness to comply with regulations
b. Willingness to respond	Acquaints him/her-self with current national, international, political and social issues voluntarily; Acceptance of responsibility for self and others;
c. Satisfaction in Response ²	Personal enjoyment identified and expressed
3. Valuing	
a. Acceptance of a value	Continuing desire to communicate effectively Growing sense of kinship to humanity
b. Preference for a value	Assumes responsibility for drawing others into group involvement; Intentionally assesses alternative viewpoints; Willingness to be identified with behaviour related to the value
c. Commitment	Devotion to those ideals which are selected; Seeks to involve others (seek converts);
4. Organization	
a. Conceptualization of a value	Abstract conceptualization; Links values to others held (such as forming judgements as to responsibility for environment);
b. Organizing a value system	Weights up alternative social policies; Brings together, possibly disparate, values;

¹ Based on Krathwohl, Bloom & Masia (1964, Appendix 'A').

² Krathwohl *et al.* note that this category has been 'arbitrarily placed at this point...[to]...remind us of the emotional component and its value in the building of affective behaviours' (1964:180).

5. Characterization by a value or value complex	
a. Generalized set (basic orientation enabling reduction of complex world)	Readiness to revise judgements in terms of new information, issues, situation; Considers alternatives and consequences rather than binary judgements Goes beyond wishful thinking;
b. Characterization (one's philosophy of life)	Develops regulation for one's personal life based on personal principles Develops consistent philosophy of life;

Appendix 'D'

Course Documentation



RHODES UNIVERSITY

Chronic Illness and Medicine Taking Behaviour Final year Elective for the Bachelor of Pharmacy

1. INTRODUCTION

1.1 Overview

The *Chronic Illness and Medicine Taking Elective* aims at facilitating a holistic understanding of the experience of people living with chronic illness, with particular reference to the range of forces that influence their medicine-taking behaviour. Using rheumatoid arthritis as an example, plus exposure to the critique from the sociology of medicine, students will critically consider traditional models of professional health care practice with respect to chronic illness. Through the medium of real patient interviews, film, and narrative studies, students will then be guided in developing an approach toward care of people on chronic drugs, which seeks to involve the patient in living well with their illness. The elective occurs over the first Semester with approximately 24 contact hours and is supported by the use of an on-line Learning Management System.

It is assumed that students taking this module will have successfully completed three years of a four-year pharmacy degree and have been admitted to the fourth year of the Rhodes University Bachelor of Pharmacy.

1.2 Credit Value

Credit value is 7.5 Credits.

1.3 Assumptions of Prior Learning

Students wanting to undertake this Elective should be able to:

- Explain the pharmacology of drugs commonly used in the treatment of rheumatoid arthritis;
 - Understand and apply the concept of pharmaceutical care to a given case study;
 - Identify and use the commonly used pharmaceutical reference texts (for example, MIMS, MDR) available to pharmacists in practice in South Africa;
 - Understand and describe potential drug related problems (DRPs) associated with a medicine;
 - Demonstrate a level of computer literacy that will enable them to access intra- and inter-net resources.
-

2. OUTCOMES

2.1 Critical Cross-Field Outcomes

Successful participation in the course will assist students in developing competence to:

- a) identify and solve problems
- b) work in a team
- c) organize and manage themselves
- d) collect, analyse and evaluate information
- e) communicate effectively
- f) use science and technology
- g) recognize problem solving contexts
- h) be culturally and aesthetically sensitive

2.2 Specific Intended Outcomes

On successful completion of this module, students will be able to:

- 2.2.1 Develop a Pharmaceutical Care Plan based on a model introduced in the class, and using data obtained from interviews with a patient.
- 2.2.2 Understand and describe the pathogenesis of rheumatoid arthritis, for the purposes of patient education and counselling;
- 2.2.3 Identify, and describe the pharmacology of, the drugs typically used in the treatment of rheumatoid arthritis (RA) in state and private health care in South Africa, for the purposes of patient education and counselling;
- 2.2.4 Understand and explain the difference between ‘disease’ and ‘illness’ in the sociology of medicine;
- 2.2.5 Understand and describe the elements of sociological critique of approaches to treatment of chronic illness;

- 2.2.6 Understand and describe the contemporary debate around the understanding of patient medicine-taking behaviour, identifying the core of the sociological critique of medical dominance in the patient – pharmacist relationship;
 - 2.2.7 Develop a theoretically supported model for pharmacist – patient interaction with respect to medicine-taking in chronic illness.
-

3. TEACHING METHODS

The course will be conducted using a combination of

- 1. lectures given by specialists in RA care;
 - 2. film, guided reflection and narrative analysis in group-based class work;
 - 3. interviews with selected patients, and recording and analysing this data;
 - 4. journal and formative mini-assessment tasks using an on-line learning management system (LMS);
 - 5. class discussion and problem-solving exercises.
-

4. COURSE/MODULE CONTENT

Rheumatoid arthritis– pathogenesis and symptoms

Rheumatoid arthritis– treatment

Pharmacology of Disease Modifying Anti-Rheumatic Drugs (DMARDs) and brief overview of non-steroidal anti-inflammatory drugs (NSAIDs)

Pharmaceutical Care Plan (Reviewed at end of course)

Patient Interviews

Viewing of, and reflection on, selected film examining HCP and patient roles in chronic / terminal illness

Disease vs. Illness – sociological concepts

Developing a critical understanding of chronic illness

Role of pharmacist in the care of people living with chronic illness

Critique of compliance / adherence

Concordance (British Royal Pharmaceutical Society)

Critique of ‘Concordance’

5. RESOURCES

- 1. All core resource material will be made available via the electronic learning management system (LMS), and will consist primarily of journal articles.
- 2. Additional resources are available in both the Pharmacy library and (with respect to sociology of medicine) in the Main Library.

3. Copies of lecture notes by visiting lecturers will be made available using the LMS.

6. STUDENT ASSESSMENT

NOTE: Overall summative assessment of this module will be undertaken through use of individually submitted Portfolios.

The final portfolio must contain *at least*:

1. A completed Pharmaceutical Care Plan (PCP) based on the format negotiated in class;
2. A minimum of a 600 (maximum 1200) word reflection on the process of interviewing a patient and drawing up the PCP, noting any learning which the student deems significant;
3. A patient information leaflet explaining the pathogenesis, treatment options, and importance of treatment of, rheumatoid arthritis. This leaflet should be designed to fit on an A4 page, using any format within the constraints of that size paper. Both sides of the paper may be used. Appropriate referencing of sources should be included on a separate page.
4. A chart for use in patient education and counselling, outlining details of drugs used in South African treatment regimens for rheumatoid arthritis (the chart *must* include full referencing details.)
5. A minimum of a 1500 word formal academic essay demonstrating understanding of, and judgement about, the illness / disease debate, using formal academic referencing.

Assessment notes:

- Neatness and clarity of presentation, especially of material intended for patient use, will be given credit;
- Each component should be linked by use of brief reflective comments.
- The Portfolio will be greatly enhanced if the document presents a unitary whole, rather than simply a collection of disparate items.
- Students are **STRONGLY** advised to retain at least an electronic copy of the contents of their portfolios following submission.

Specific Outcomes (On successful completion of this course students will be able to...)	Assessment Criteria (Students will provide evidence that they can...)	Assessment Tasks (The evidence will be gathered using...)
1. Develop a Pharmaceutical Care Plan based on a model introduced in the	• Use a given interview form to obtain and accurately record	• Interview (s) with a selected patient; • Submission of a completed

Specific Outcomes (On successful completion of this course students will be able to...)	Assessment Criteria (Students will provide evidence that they can...)	Assessment Tasks (The evidence will be gathered using...)
class, and using data obtained from interviews with a patient.	○ information regarding a patient's personal details; illness history; medicine use; ○ the patient's understanding of their illness; ● Identify actual and potential DRPs; ● Propose an appropriate pharmacist's response to the DRPs aimed at enhancing a therapeutic regimen that includes, but is not restricted to, safe medicine-taking behaviour;	Pharmaceutical Care Plan (PCP) for comment. ● A completed PCP to be included in Portfolio (Summative).
2. Understand and describe the pathogenesis of rheumatoid arthritis, for the purposes of patient education and counselling;	● Identify the commonly understood clinical features of rheumatoid arthritis; ● Identify the primary sites of impact of RA; ● Explain the pathophysiology of the disease; ● Identify the main diagnostic symptoms and tests used in diagnosing RA. ● Explain the commonly understood progressive course of RA; ● Describe features of the impact of RA on health-related quality of life; ● Use language and illustrations appropriately and with sensitivity to the needs of potential patients.	● Journal entry using online LMS; (Formative) ● A patient information leaflet (see 6.3 above) (NOTE: this leaflet must be submitted in English); (Summative)
3. Identify, and describe the	● Accurately list and give the drug names	● Journal entry using online LMS;

Specific Outcomes (On successful completion of this course students will be able to...)	Assessment Criteria (Students will provide evidence that they can...)	Assessment Tasks (The evidence will be gathered using...)
pharmacology of, the drugs typically used in the pharmaceutical treatment of Rheumatoid arthritis in state and private health care in South Africa for the purposes of patient education and counselling;	of the major NSAIDS and DMARDS; • Describe their pharmacological action; • Accurately identify main side-effects of each drug; • Accurately identify main contra-indications, both drug and dietary, identifying in particular the medication used by the patient interviewed. • Use language and illustrations appropriately and with sensitivity to the needs of potential patients (NOTE: this chart must be submitted in English).	(Formative) • A chart for use in patient education and counselling (see 6.4 above); (Summative)
4. Understand and explain the difference between ‘disease’ and ‘illness’ in the sociology of medicine;	• Offer a description that includes the elements of formal definitions included in the literature; • Outline the distinguishing features of both the bio-medical and sociological perspectives on illness / disease;	• Class discussion and LMS journals; (Formative) • 1500 word formal academic essay (see 6.5 above); (Summative)
5. Understand and describe the elements of sociological critique of approaches to treatment of chronic illness;	• Identify the main features of the critique by the sociology of medicine of the biomedical model; • Apply the understanding of illness to their pharmaceutical care plan; • Suggest ways in which the bio-medical and sociological paradigms can be linked to the benefit of the pharmacist’s relationship with people living with	• Class discussion and LMS journals; (Formative) • 1500 word formal academic essay (see 6.5 above); (Summative)

Specific Outcomes (On successful completion of this course students will be able to...)	Assessment Criteria (Students will provide evidence that they can...)	Assessment Tasks (The evidence will be gathered using...)
	chronic illness.	
6. Understand and describe the contemporary debate around the understanding of patient medicine-taking behaviour, identifying the core of the sociological critique of medical dominance in the patient – pharmacist relationship;	• Describe the problem of medicine-taking behaviour and its impact on patient health, the health-care system and wider social implications; • Define ‘compliance’ and ‘concordance’; • Identify and explain the strengths and weaknesses of each model and briefly explain the implications of adopting each model for pharmaceutical practice; • Briefly describe Norman Gee’s understanding of ‘Discourse’ and how this understanding offers a vehicle for critique of health-care practitioner – patient interaction surrounding chronic illness;	• LMS Journal responses; (Formative) • 1500 word formal academic essay (see 6.5 above); (Summative) • Final Pharmaceutical Care Plan; (Summative)
7. Develop a theoretically supported model for pharmacist – patient interaction with respect to medicine-taking in chronic illness.	• Identify DRP’s in RA, but suggest potential generic DRPs in all chronic illness; • In the light of the debate around medicine-taking behaviour, take a position informed by the literature and describe the pharmacist’s role in supporting a patient living with chronic illness;	• Initial PCP submission (Formative) • 1500 word formal academic essay (see 6.5 above) (Summative) • 600 word reflection (see 6.2 above); • Final PCP submission included in Portfolio. (Summative)

7. EVALUATION

Evaluation will be carried out by means of a Small Group Instructional Diagnosis conducted by a staff member who has not been involved in the class. The nature of an SGID ensures that in the plenary, students are made aware of the consensus of the class. A copy of the final evaluation report will be made available via the LMS used to support learning in the course, which students can access at any stage. A copy of the report will be sent to the HOD (Pharmacy) and the Professor of Pharmacy Administration and Practice.

Course Outline - 2004

Friday, 27 Feb (2 nd period) Introduction	In this session we will look at your hopes and expectations for the course, why I believe it is important, and at the structure of the course, the outcomes, assessment and evaluation of the course. We can check and negotiate some of the dates for the
Tuesday, 2 March, (6 th period) Rheumatoid Arthritis – mechanics of the disease and symptoms	Course leader: Dr Celia Jameson (Specialist Physician)
Friday, 5 March, (2 nd period) Rheumatoid Arthritis – treatment options	Course leader: Dr Celia Jameson (Specialist Physician)
Tuesday, 9 March, (6 th period) Rheumatoid Arthritis – pharmacy response	Lecturer: Dr Anne Kench (Pre-lecture task: look up drug types listed in reading resource, and identify South African drug names.)
Friday, 12 March, (2 nd period)	Pharmaceutical Care Plan Using the PCP that you have begun using in PAP IV CEP, we will examine the use of that framework for your interviews with your patients.
Week beginning Monday 15 March	Interviews with patients (Own arrangements – details to follow) You will be assigned a patient with whom you will work for the two interviews. You will need to contact that patient and arrange a time and place to meet with them. We will TRY and arrange for you to meet them at the RA clinic at Settlers, but some are working and unable to leave work.
Tuesday, 23 March	Pharmaceutical Care You will present elements of your care plans (Final drafts must be submitted by 12:00, 13 April 2004 - preferably, 12:00, 24 March) to the class. We will discuss these plans and highlight items of concern and that need further investigation. Interviews with patient / s
April Vacations	

Friday, 16 April Arrange session to view film (1.5 hours)	Preparation session for film Please note this date! It is important to ensure that you attend this session as we will prepare for the viewing of the film, identify tasks, incidents to look out for, and specific themes to identify. We will also arrange a date / time to see the film, perhaps over coffee one evening (it is only 1.5 hours long!)
Tuesday, 20 April	Guided reflection on film Following the principles of the North American "WitFilm Project", we will review the film identifying specific issues and themes as they relate to care of people living with chronic illness (and palliative care). Visiting lecturer: Prof H v.d. Mescht (Education) will facilitate this session. The interpretation of film and narrative is a speciality of Prof v.d.Mescht's.
Friday, 23 April	Disease vs. Illness – sociological concepts Please ensure that you complete the readings set for this (and the next) sessions BEFORE the session!
Friday, 30 April (NB Tuesday, 27th is a holiday)	Chronic illness We will examine the concept of chronic illness from a sociological perspective, noting some of the implications of chronic illness for pharmacy and medicine.
Tuesday, 4 May	Role of pharmacist in chronic illness care
Friday, 7 May	Critique of compliance / adherence Looking at a range of critiques of the concept (and underlying approach to patient care) of "compliance"
	
Tuesday, 11 May	Critique of compliance / adherence Follows on from Tuesday's session. Implications for practice?
Friday, 14 May Concordance (British Royal Ph'cy. Soc.)	Examine the model proposed to replace models of pharmaceutical care based on "compliance"

17th - 21st May - readings on concordance, and revisit Care Plans (Re-interview patients if required.) As with previous interviews - opportunity to revise Patient Care Plan.	
Friday, 21 May	Critique of ‘Concordance’ Great idea, but will it work? (Hospital and retail / community settings - challenges and possibilities). You've had time to read the readings, and look at how you may apply this in your patient care plans - now, how practical do you think the idea of a concordant relationship with patients living with chronic illness, is?
25 & 28 May	Present (re-)draft of care plans You will have the opportunity to present your care plans to facilitate peer feedback prior to including them in your final portfolio. It will be especially important to think about defending your model of patient care (compliance-disease; concordance-illness; etc.)
Evaluation (Date to be arranged)	A brief course evaluation by ADC staff member. This will again be an opportunity for you to consolidate your ideas.
FINAL PORTFOLIOS TO BE SUBMITTED BY 16:30, Monday 2 August 2004	

Appendix ‘E’

Rheumatoid Arthritis – an overview

(See Merck 2004 on attached CD for more details)

Although the cause of rheumatoid arthritis (RA) is unknown the condition is generally described as an autoimmune disease characterised by inflammation of the joints (NIAMS 1999; Gurenlian 2002; Merck 2004). As Lee and Weinblatt (2001) indicate, RA affects far more than joints, and is systemic, affecting membranes throughout the body (Figures E-1 and E-2, below). These figures provide some indication of the way RA impacts on the lives of those who experience it:

Symptoms

- Joint swelling
- Pain/stiffness (commonly in morning and lasting >1 h)
- Weakness
- Deformity
- Fatigue
- Malaise
- Fever
- Weight loss
- Depression

Articular characteristics

- Palpation tenderness
- Synovial thickening
- Effusion (early on)
- Erythema (early on)
- Decreased range of motion (later on)
- Ankylosis (later on)
- Subluxation (later on)

Distribution

- Symmetrical (especially later on)
- Distal more commonly than proximal
- PIP, MCP/MTP, wrist/ankle more commonly than elbow/knee, shoulder/hip (PIP = proximal interphalangeal joint. MCP=metacarpophalangeal joint. MTP=metatarsophalangeal joint.

Appendix Table E 1: Clinical features of RA (Lee & Weinblatt 2001: 903)

Organ	System Involvement
Skin	Rheumatoid nodules, vasculitis
Ocular	Keratoconjunctivitis sicca, iritis, episcleritis
Oral	Salivary inflammation (sicca symptoms)
Respiratory	Pulmonary fibrosis, pleural effusion, cricoarytenoid inflammation
Cardiac	Pericardial inflammation, valvular nodule formation, myocarditis
Neurological	Mononeuritis, nerve entrapment, cervical instability
Hepatic	Increased aminotransferase concentrations
Haematological	Anaemia, thrombocytosis, leucocytosis, lymphadenopathy
Felty's syndrome:	splenomegaly, thrombocytopenia
Vascular	Vasculitis

Appendix Table E 2: Extra-articular involvement of RA (Lee & Weinblatt 2001: 904)

RA affects approximately 1-2% of the population with women making up the majority of sufferers in a ratio of 2.5:1 (NIAMS 1999; Lee & Weinblatt 2001; Gurenlian 2002; Merck 2004). Onset of RA is frequently unnoticed by the patient and is unlikely to be suggested by available medical tests until approximately two years after onset by which time joint damage has begun. In most cases RA is first noticed as joint pain in a person's small joints of their hands and feet, after which the synovial membranes of larger joints (knees, elbows, shoulders, neck, spine and hips) become affected (Lee & Weinblatt 2001; Gurenlian 2002). Graphic indication of the affect of RA on smaller joints is visible in the images below (Appendix Figures E 3 & 4):

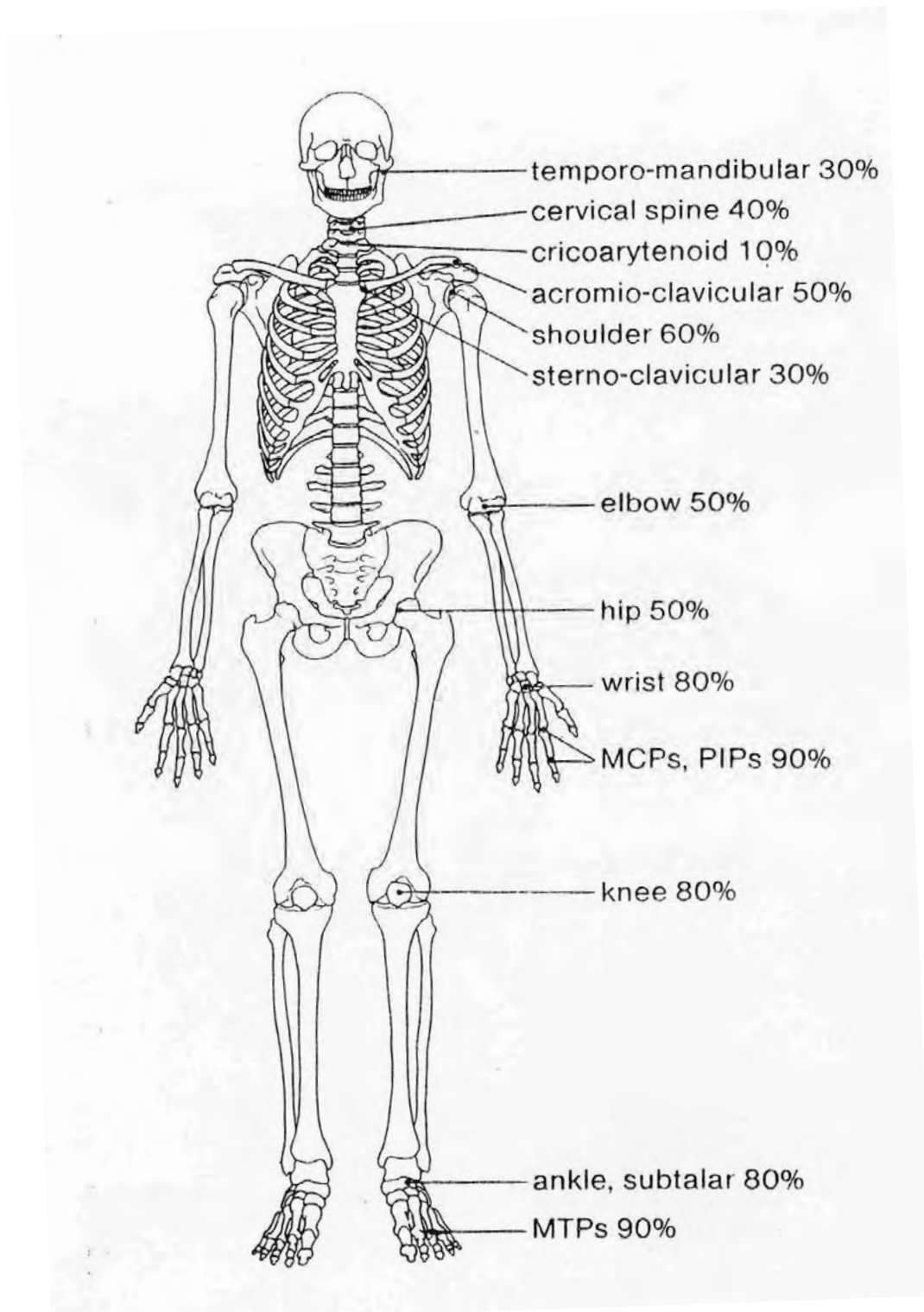


Appendix Figure E 4: RA Hands, Surgical Tutor (n.d.)



Appendix Figure E 3: X-ray Science Museum (n.d.)

Appendix Figure (E.5) below illustrates the frequency of joint involvement in people living with RA.



Appendix Figure E 5: (Jameson, Personal Communication, 2004)

Appendix 'F'

Consent forms

S.1.



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Negotiating medicine taking in Chronic Illness

CONSENT FOR RESEARCH INTERVIEW

Thank you for agreeing to participate in this research project aimed at developing pharmacists' understanding of how living with chronic illness impacts on medicine taking behaviour. Respondent confidentiality will be maintained at all times with the proviso that the researcher (Mr Kevin Williams) will know your name and will be the only person with access to both your name and an allocated Respondent Code. Only you and the researcher will have access to interview tape(s) and transcript records of interviews. You will be allocated a respondent code which will be used in the transcripts and in any further use of interview material. No information gathered through this project will be made available in such a way that either yourself or any person mentioned by yourself can be identified by anyone except the researcher. No information you give to the researcher, aside from your assessment portfolio, which must be accessed by teaching staff, will be disclosed in an identifiable manner to any person other than the researcher without your prior written consent.

You are respectfully requested to avoid identifying patients, medical practitioners, pharmacists or any other members of the health care profession by name in any of the material.

Transcripts of interview material will be returned to you for comment prior to being utilized in the research project, and in a form using your respondent code.

What will the project involve?

The study involves a questionnaire, all material submitted for the Pharmacy IV Elective, plus a semi-structured interview of a maximum of 60 minutes at a venue mutually agreed upon by the researcher and yourself following the completion of the elective. The interview will seek to understand further how you have experience the impact of the elective, and how you understand the concepts of chronic illness, medicine-taking behaviour and the role of the pharmacist.

You are free to withdraw from the project (without jeopardizing your participation in the Elective) at any stage, although it is requested that you inform the researcher of such a decision.

Attestation of agreement and confidentiality

I, Kevin Frank Williams (the researcher) do hereby swear that all information obtained as a result of these interviews will be treated in such a way that the confidentiality of the provider of that information will be maintained.

Signed: _____ Date: _____

I,(research participant) do hereby acknowledge that I have been informed of the nature, method and purpose of this research project, and have given my informed consent to participating in the project provided that my confidentiality is observed. I give permission for interview transcripts, with my identity concealed, to be used for the purposes of this research project.

Signed: _____ Date: _____

P.1.



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CONSENT FOR RESEARCH INTERVIEW

Thank you for agreeing to participate in this research project aimed at developing pharmacists' understanding of how living with chronic illness impacts on medicine taking behaviour. Patient confidentiality will be maintained at all times with the proviso that Dr Jameson, the researcher (Mr Kevin Williams) and the student interviewing you will know your name. The students and the researcher alone will have access to interview tape(s) and transcript records of interviews. You will be allocated a patient code which will be used in the transcripts and in any further use of interview material. No information gathered through this project will be made available in such a way that either yourself or any person mentioned by yourself can be identified beyond the persons noted above. No information you give to the interviewer will be disclosed to Dr Jameson, nor, in an identifiable manner, to any person other than the students and the researcher.

You are respectfully requested to avoid identifying medical practitioners, pharmacists or any other members of the health care profession by name during the interviews.

Transcripts of interview material will be returned to you for comment prior to being utilized in the research project, and in a form using your patient code.

What will the project involve?

The study involves two interviews of a maximum of 60 minutes each, at a venue mutually agreed upon by the researcher, the interviewing student and yourself. The interviews will be approximately eight weeks apart. In the first interview the interviewers will ask you questions relating to your experience of Rheumatoid Arthritis and the treatment which you are receiving for this. You may also be asked to

indicate other medical conditions and medication which you are taking, including so-called “complementary therapies” (homeopathic / natural medicines). The second interview will seek to understand further how you experience the impact of both the condition for which you are being treated, and the treatment itself with particular reference to medication. The primary purpose of the interview(s) is to provide the final year pharmacy students interviewing you with a greater insight into the needs and expectations of people living with chronic illness.

Attestation of agreement and confidentiality

I, Kevin Frank Williams (the researcher) do hereby swear that all information obtained as a result of these interviews will be treated in such a way that the confidentiality of the provider of that information will be maintained.

Signed: _____ Date: _____

We, (student interviewers) do hereby swear that all information obtained as a result of these interviews will be treated in such a way that the confidentiality of the provider of that information will be maintained.

Signed: _____ Date: _____

I,(interview participant) do hereby acknowledge that I have been informed of the nature, method and purpose of this research project, and have given my informed consent to participating in the project provided that my confidentiality is observed. I understand that I may withdraw from the project at any stage prior to submission of the thesis. I give permission for interview transcripts, with my identity concealed, to be used for the purposes of this research project.

Signed: _____ Date: _____

Appendix 'G'

Student Reflection Statements from Final Portfolios

NOTE:

- These documents have been OCR scanned from original portfolios.
 - Names and identifying comments have been removed. In-text indications have been made where documents have been altered.
 - Formatting has been altered during the scanning process.
 - No other changes have been made, and spelling and grammar is original.
 - Codes preceding each document refer to student participant.
 - Some of the students are English Alternate Language speakers.
-

1A - Reflection Statement

The process of interviewing the patient and drawing up a pharmaceutical care plan was very beneficial and I learnt a lot from it.

The actual process of interviewing the patient tested my communication skills, and I learnt that interviewing a patient is not as easy as it sounds. One has to be very alert and very observant and as interviewers we need to pick up on both the verbal and non-verbal cues, as those cues are a source of information. With my patient, specifically I realized later that I did not really read in between the lines of what she was saying in the interview until I read the transcript in detail. Therefore I found this, as one of my weaknesses during the interview process and that was a learning experience in itself. Also, during the interview process, I learnt that patients have magnificent ways of subtly concealing important information, especially when this information is with regards to not completely following or obeying their therapeutic regimen. Therefore, one has to slowly draw this information out of the patient. Patients don't always want to share all their information and I found that it is something you have to be aware of and then use your discretion and decide whether you want to get that information out of the patient or not. As interviewers we need to be sensitive to this, and also respect a patient's privacy to information.

In terms of drawing up the pharmaceutical care plan, I did not find that drawing up this pharmaceutical care plan was very difficult, as the patient I was interviewing was very co-operative and the concept of Rheumatoid Arthritis was not new to her especially as her (***) suffered from rheumatoid arthritis. She had some knowledge on the treatment and knew what she could expect from the illness. This aspect made drawing up the care plan a lot easier, as the patient was knowledgeable to a certain extent about her condition and medication and understood the importance of compliance and adherence to therapy. Therefore this helped a lot.

However, I think the most difficult part in drawing up the pharmaceutical care plan was with regards to the interventions. On my pharmaceutical care plan I stated that I would intervene by monitoring the patients treatment, check on the patients adherence and compliance with regards to her medicine taking, as well as deal with actual and potential drug-related problems. The difficulty arose in how to go about carrying out these interventions, for example, how do I know that the patient is compliant or adherent, how can I help the patient to be compliant or

adherent, how do I intervene and monitor? When do I intervene? These were the difficult aspects of the care plan. Probably because I am not a practicing pharmacist as yet, I do not have much experience with regards to interventions that are realistic and that can actually be practiced. However, the care plan was a good learning experience to prompt me to start thinking about interventions and how I can go about them. I learnt from doing the PCP plan the importance of coming up with interventions during drug-therapy, because if we as pharmacists don't intervene we are effectively doing nothing for the patient or for the health of the general public.

Another aspect that gave some difficulty was not directly with regards to the care plan but rather with the patient. This patient was petrified about her RA, because she had seen her (***) suffer with RA, who had eventually become crippled due to it. This patient is very petrified with the final outcome of this disease and because of this fear, is not willing to discuss her illness, does not want to know anything additional about RA or her medication, than is absolutely necessary. This would make it difficult with regards to helping the patient because of her avoidance to really acknowledge her illness, talk about her feelings and what she is going through. Also the patient's unwillingness to find out about her condition and therapy, as well as discuss it, would make it difficult to have implementation of the care plan in practice. This is a challenge for pharmacists, to help patients who are actually avoiding or denying their disease. With this patient I could see that she would want help and would appreciate it, but she would be the type of patient whereby the pharmacist would have to be sensitive. In this situation specifically, I think applying the model of concordance between the patient and pharmacist would work brilliantly as this model is patient centered and there is a therapeutic alliance between HCP and the patient.

Doing a PCP was a good learning experience in drawing up drug-regimens and I learnt the importance of having full knowledge about all the drugs in a complex regimen, because the side effects and drug interactions have the potential to cause adverse reactions in a patient if these are not fully investigated or at least seen as potential drug-related problems. The PCP plan also taught me to be thorough in my research and recognize all aspects of patient care, from constructing drug regimens, to monitoring and intervening.

2L Reflection Statement

In my four years of pharmacy I have had very limited contact with actual patients. Our brains are saturated with the theory, but once the textbooks are closed the real world proves to be a very different place. In the same way that we have discussed how our patient's medicine taking behavior is affected by what they have experienced, our knowledge of living with a chronic illness means nothing until we have experienced it or at least are able to view it through someone else's understanding of their experience. This is what drew me towards this elective. The chance to interview a person living everyday with an illness and disease that affects their lives in so many ways was an invaluable experience and I now feel that I have far more insight into a patients needs and my role as a pharmacist.

One way to find out how people understand their world and their life is to ask them. With this in mind I set out to gain as much understanding about my patient's experience of her rheumatoid arthritis as possible. The interviewing process was especially valuable to me because like so many other pharmacy and medical students, I am not a peoples persons and learning the skills of building a relationship with a patient is very important to me. I think it is very important to be aware of what kind of person you are interviewing when considering what

kind of approach to take. An uneducated elderly woman will have very different expectations and values than a young, extremely well educated lady such as the one myself and [Name deleted] interviewed. Because we are still students I imagine she expected a large amount of respect from us, but even if we were qualified pharmacists, I think she would expect us to acknowledge her educational status and extensive knowledge of her own disease. We approached the interview in a very different way than if we were interviewing a less educated patient with regards to the language we used, the tone of voice and the overall control we took of the interview. The theoretical knowledge she has of her disease put us to shame and we were able to gain so much from listening to her physical, but more importantly her emotional journey. I think it is important for health professionals to be able to read between the lines. Even though our questions as pharmacists are very clinical, the way a person answers each different question, the language they use, the look on their faces can tell so much about what they have been through and where they are emotionally at the time of the interview. When I left the interview I felt that the patient was very well adjusted and had come to terms with her disease. Yet reading through the transcripts I was amazed to see how much I had not picked up in the interview. Often a patient will show that they want to tell you more and it may be very comforting to talk to someone they have respect for. Letting a patient tell you their whole story can be surprisingly valuable to us with regards to ensuring drug adherence and I think pharmacists miss many important details because what they think are the right, important questions are actually the least valuable.

One of the most important things I learnt from this elective was that it is important to have constant interaction with your patients so that you can build a relationship where each party respects the other. I feel that this is essential to the pharmacist patient relationship.

3C. Reflection Statement

Upon reflection of my initial feelings toward conducting this interview, I remember clearly my anxiety regarding the questions the patient may have concerning her medication. With no access to patient files or data, we were quite obviously placed in a situation likened to that of a pharmacist meeting with a new patient, a learning experience beyond the constraints of a lecture theatre. Fortunately it was not expected of us to offer advice or comment on the treatment of the patient, but rather following a structured questionnaire and emphasizing an observation and assessment of the patient's understanding and experience of Rheumatoid Arthritis (RA) and the treatment she is receiving. It is through such an interview that we are reminded of the necessity of a pharmacist to listen to, and indulge in an empathetic attitude toward the patient in their disease state.

The interview process itself ran efficiently as my partner and I dealt with different areas so as to allow each a chance to speak and prompt the patient. In order to offer our full attention to the patient, while one person was asking the questions/talking, the other acted as a scribe to ensure all details were noted. Working in this partnership, we found it easier to retain all the information as provided by the patient and it allowed an opportunity for us to observe and correlate the different perspectives each of us received from the interview. We were fortunate to interview a patient who appeared to be very compliant toward her medication regimen. It was noteworthy the 'enthusiasm' the patient displayed toward the various forms of medication she had previously taken and the course she is currently on, despite any adverse drug reactions she may have experienced. Her friendly nature and willingness to answer our questions turned the interview rather into a pleasant 'chat' where both the interviewee and interviewer felt comfortable. However, I do realize that this was an ideal situation- a far cry from the many

confrontations we shall experience in the pharmacy and the ideal adherent patient.

From the interview, we were assured by our patient that she was adherent to her medication regimen. The trust the patient described with her doctor, the pain the medication has previously alleviated and her fear of the consequences if this medication is not taken, are all motivating factors for the patient and would lead us to believe her adherence. Further prompting did reveal use of non-prescription medication taken as the patient tries to benefit from a more holistic, empathetic approach (such as advice offered to her by her sister). As this form of therapy tends to change/discontinue haphazardly we are uncertain if her doctor is always made aware of their use.

Hence, an overall perspective of the interview indicated an adherent, willing patient looking for the best from her therapy and even though experiencing some adverse drug , reactions, she left it in the supervision of her doctor. Our patient is also trusting in the benefits of non-prescription medication, probably unaware of possible drug interactions. However, in drawing up the pharmaceutical care plan, correlating questions and eliminating inconsequential details started to narrow information down to particulars significant to the failure or benefit of her medication regimen. There was suggestion that medication for other indications (co-morbidities) may have either been disregarded or used incorrectly. Research into the different medicaments, showed drug interactions or side effects either not mentioned by the patient or otherwise appeared to be causative of a serious side effect that she may have complained of. While I attempted to explain these problems as best I could, I did find I struggled in instances where I would assume her to be taking a certain medication regularly- hence resulting in a symptom, but for a second drug reaction, would have to assume that the same medication is not being taken as prescribed hence resulting in that second reaction, of which she had complained. This leads me to an understanding of how difficult it is for a pharmacist or doctor to attempt to understand a problem as presented by a patient, when one has little knowledge on the exact compliancy and will have to make assumptions regarding with which drug the problem may lie.

The standpoint I took when attempting to enhance the therapeutic regimen, was one to incorporate an 'either/or' situation: rather than assuming that one medicament was the cause of the problem and just eliminating it (as without the ability to query into the doctors prescription), I rather offered a process to attempt to find the causative factor through a series of trial and error. Alternative therapies were offered within the care plan in instances where it may be the problem of which I assumed. While it is rather frustrating to not be able to query the therapy as prescribed, so as to make clear deductions, it was possibly more beneficial as a learning experience as we had to approach each adverse situation from a number of angles. This encourages me as a future pharmacist to think broader when dealing with a medication regimen and potential problems, rather than jumping to and acting upon initial conclusions.

The interview process and drawing up the pharmaceutical care plan has developed in me a better understanding regarding chronic illness and the medicine taking behaviour of such a patient. Developing the adherence management plan in potential concordance with the patient, and researching into the best adherence aids, emphasized the importance of a partnership in the health care of the patient. It is important to encourage a responsibility toward their medication regimen, of which requires counseling and information. The above methods along with a more 'multi-disciplinary' approach from all health care workers involved, including stress management and relaxation techniques for instance, will offer the patient a more holistic approach to their chronic illness. This will ultimately encourage adherence and management of the illness, and avoid unnecessary adverse drug reactions.

4L Reflection Statement

Rheumatoid arthritis (RA) is a degenerative autoimmune disease that is not curable;

however with drugs it can be controlled. It mainly affects joints. Rheumatoid arthritis is typically seen as an inflammation and swelling of the joints, especially the hands and wrists. This condition can occur in middle aged, but can also affect any one.

RA is a chronic inflammation condition like other chronic conditions it requires long term-treatment. It is important to educate the patient about the disease and ensure that clear understanding is achieved. It is through this understanding that control and the well being of the patient can be achieved. Like other chronic conditions, high level of adherence to drug therapy is required; however drugs in general pose a big problem of unwanted side effects. With regard to RA medication, which is multi medication, there should be a close monitoring of drug adverse effects to achieve the optimum benefit and minimize side effects. It is therefore important that patients are well aware of what to expect and what to do in case these problems arise.

The complications of the disease may also lead to different lifestyle modifications, this is not an easy thing for a person to achieve, but through good communication skill and negotiations patients are empowered to participate in decision making to wards their respective health and body. Patients can not be forced to take their medication but can be encouraged to do so. Patient education about the disease and the consequences of not taking treatment should be put forward and benefits and disadvantages of not adhering to the treatment and modification of other habits.

In all chronic medication it is important to take into account the background, culture and religious beliefs of the patient. The patient perception, beliefs and social influences towards rheumatoid arthritis (RA) are very important in helping the doctor or pharmacist to identify the necessary approach and to enable proper communication. However good communication skills are necessary to help the patient express his/her views. It is important to determine patient understanding of the disease. The importance of medication and medication taking behavior and compliance can only be picked through best communication methods.

Long term medications are easy to forget, more over patient that suffer form RA may have other complication along. It is at this juncture that pharmacist role as drug counselor is very important. Because of the nature of the disease and drugs used, it very important to make sure that proper communication is achieved or the patient life maybe endangered. This means the health professionals should make sure that together with the patient they eliminate the stigma behind the disease, so that patient can openly discuss the condition and be able to seek professional advice at any time any thing happens. It is important to ensure that the patient knows her medication well, and what s/he can avoid or not use concurrently with RA medication.

Good communication skills are very critical, it is therefore important to change approach to facilitate better communication. Pharmacists should be drug counselors and educators, for the chronic and acute illness. Patients should be told about their drugs and clearly understand why and how to use their medication as well their storage. Most health professionals fail to pass their knowledge properly to their patients and among themselves, this may result in loss of trust and poor services. Patients should be given respect, and negotiations to an agreement on how to take medication should be reached, so that all compromises to optimize drug benefit as well as freedom of expression and communication can be achieved.

All chronic treatment has complications, however professionals are there to help and understand their patients. Is it through this mutual understanding and patient-health professional good relationship that cost and wastage of drugs can be minimized. Through this relationship that patients can have a better understanding and support from their friends and the society at large. It is important to note that RA management does not rely on medication alone, but as well as the support and understanding of the disease. Drug taking behavior can drastically change with proper approach and communication. Hence concordance will address many issues that were excluded by compliance and adherence as methods of patient approach. Health professional should communicate in language that is understandable rather than the complicated medical language to enable their patient to have a clear picture of the conditions.

Conclusion

Pharmacists are in a good position to encourage patients to ask questions about their medication, and address any concern or preference they hold about drug therapy. However the attitude of the patient is predominantly affected by the health settings, communication with either the doctor or pharmacist. It is therefore important to identify these aspects and be patient. Patient need to be educated about their disease and medication, however this should be broad, so that the patient perceptions and beliefs are taken in to account. It is important to find what patients think about their disease status, with respect to their cultural, social and religious beliefs. This can help to reach a compromise as to what medication to be given, since some people do not want to be considered sick.

For concordance to exist, doctors and pharmacist need to develop respect for their patient's beliefs and wishes. They should also appreciate the background, experiences and preferences of the patient. All the health professionals for the benefit of the patient and for the optimum outcomes should work as a team, however proper diagnosis both from disease based and drug related problems are very important to win the confidence of the patient.

5A- The interview process

I chose to do chronic illness and patient care for many reasons one of them being that I found the thought of working with actual patients very intriguing. People, how their minds work and influence their behavior interests me a great deal, but as the interview day grew closer I began to feel more and more nervous. As students we have not had much contact with actual patients and every time we do it feels as though we have been thrown in the deep end. Of course we have made sure we know all the theory, but putting it into practice is a very different story

People are so different from one another, thinking about what kind of person you may encounter and how they will react to you and of course how you are going to deal with their reactions being sure always to maintain a professional attitude, really puts on the pressure. Because such a big part of our course is based on the idea of concordance as opposed to compliance, I tried to think about bringing in some of these ideas during our interview process. I think a big part of building the desired relationship with a patient is getting them to trust you and to simply like you and the way you treat them. This to me is the most difficult part of a concordant relationship because every person's personality is so different and in my opinion we as health professionals will have to adapt our approaches accordingly if we want to bring in concordance successfully.

Luckily I managed to surprise myself on how well I think I handled this interview for an amateur. I had prepared myself to be able to adapt depending on the person I would encounter

and I think I managed this rather well. I must say the lady [Name deleted] and I interviewed was one of the easier personalities I expected to encounter. She was friendly and open and already very trusting of the health professionals she had dealt with. She gave the impression that she was ready to welcome anybody who may be offering help, with open arms and was willing to do anything to help us. She also showed a great amount of respect for us and seemed almost honored to have us interview her. I have seen this kind of attitude during interviews with patients in the township. It seems that patients who feel they are very much less educated or of a lower class have this sort of attitude towards health professionals. These patients are fairly easy to work with face to face, however they still may not adhere to their drug regimen at home when you are not there to motivate them everyday.

Mrs. m's positivity towards her treatment and willingness to co operate with the doctor was mainly due to the fact that she had seen for herself what could happen to her if she did not take it seriously. This "Fear" takes on a very important role in drug adherence and even though we don't want to give our patients a negative attitude it may be the only way to build adherence. I think it is very important to visually show patients what could happen to them if they do not adhere to their treatment. Unfortunately, for some patients that fear is not a reality for themselves and they continue to live in denial until they experience it themselves, and then, it is probably too late.

[Name deleted] and I both took a very gentle friendly approach to Mrs. M. Our people skills seemed to adapt to her personality immediately. We both had a very caring, understanding tone of voice. I got the impression that she needed to tell her story the way she wanted to and so we just ran with it and let her talk while we absorbed the key information. I felt this gave us more insight into who she was and was be very valuable when drawing up an intervention suitable for her as an individual as opposed to asking the specific questions from our questionnaire, which may have been very limiting. At the end of the day, if you don't know what type of person you are dealing with, there is a good chance your intervention will fail and you will not have a concordant relationship leaving a continued risk of non-adherence. One plan will not work for every patient, we have to be flexible and think deeper in designing our interventions to ensure adherence.

I was very impressed with our patient's attitude and I felt there was not much need for external intervention. She has taken her health in her own hands and made the right decisions for herself. However, a patient being as trusting as she is may also have a negative side. Mrs. M trusts everything she is told and doesn't question or understand much, other than the pain. With some this may lead to adherence problems. A patient still needs to understand their disease and the treatment so as to empower them. They need to be in as much control of their health as anyone else is.

I must say I was hoping for a patient with a more challenging personality, but of course even for Mrs. m it doesn't just end there. Her attitude may change with time and again it is the health professionals job to pick it up and find ways to make sure it doesn't and just because she was a pleasure to work with and seemed the model patient there are always little potential problems that we are trained to watch out for and must be careful not to forget this.

6F - Reflection Statement

A patient's medicine-taking history is extremely important in drawing up the best possible pharmaceutical plan. The process of interviewing a patient was, for me, quite daunting at first.

However, it has provided me with certain tools necessary for an effective and efficient interaction with patients.

With just over three years of my study of pharmacy behind me, this was the first time I came into direct contact with patients. The patient I interviewed, Kate*, spoke English fluently, making the interview easier to conduct. Speaking to patients in languages they are comfortable with, I believe, helps to build a stronger pharmacist-patient relationship.

For an effective interview, I learnt that being a good listener is just as important as asking the right questions. People are quite complex. Asking the right questions in order to draw up the best possible pharmaceutical care plan can be quite challenging. Asking open-ended questions helped to elicit a more patient-centred focus as opposed to closed-ended questions. But when time is short, direct questions may be the only way to do business. However, direct questions often do not help us understand things from a customer's point of view and they rarely give the impression of caring (even when we do passionately care).⁶ The questions provided served as a good guideline, however, some deviations were necessary. For instance, the order of the questions needed to be altered. I also found that letting the patient speak her mind provided some valuable information.

A new relationship between prescriber has been described. The term concordance has been introduced. While compliance describes the degree to which the patient follows the prescribed regimen of medicines, concordance describes an agreement between a patient and a healthcare professional about whether, when and how medicines are to be taken. Concordance therefore refers to the creation of an agreement that respects the beliefs and wishes of the patient, and not to compliance, the following of instructions.¹

The pharmacist-patient relationship is an important influence on whether the patient takes his/her medication. Patient counselling is one of the key elements of patient adherence. The patient interview has also taught me how important the role of the pharmacist is in not only providing essential information, but also in answering patient concerns. Furthermore, it is important to be vigilant with regard to drug-interactions, and to fit in the patient's drug therapy with his/her lifestyle.

Interviewing the patient in their work or home environment helps to paint a clearer picture when drawing up a pharmaceutical care plan that is patient-specific. Being open-minded when interviewing patients, as well as not letting one's bias influence the drawing up of the most effective pharmaceutical care plan, are both essential. In addition, I realised that one should deconstruct one's own assumptions in order to comprehend the patients' assumptions.² It was also important to take into account when drawing up the care plan that it is the patients' agendas and not that of the health care professional's that determine whether patients take medicines.¹

Furthermore, we commonly assume that other people think like us, but we rarely check that assumption. My patient and I were different, and understanding how these differences would affect the interview process was important.² For example, I'm in my 20's and my patient was middle-aged. She comes from a disadvantaged background whereas I do not.

I found that, with the patients' permission, recording the interview can be quite helpful. The transcript assisted in filling in gaps i.e. to ensure that essential information was not omitted when deciding on the best possible care plan for the patient.

Kate* volunteered a lot of important information, which made the interview easier to conduct. She felt more or less well managed and seemed comfortable in discussing changes she feels

needs to be made with her doctor. This mutual respect between doctor and patient was quite impressive.

One of the difficulties that I encountered was that the patient did not remember some of the names of the medication she was taking, and when she had started, and where relevant, had stopped therapy. Putting all the information obtained from the interview into perspective was also quite time-consuming.

I learnt that the ability to manage symptoms associated with a chronic condition has enormous implications for living with a semblance of normalcy in a patient's life.³ In addition, a variety of factors affect decision-making in the context of chronic conditions.⁴

Many patients often have more than one chronic illness at a time. Each illness has its own management regimen and, with this accumulation, the regimens may become competitive.⁴ For example, Kate* has had Rheumatoid Arthritis for many years and was recently diagnosed as being hypertensive. The treatment she's on for these two conditions interfere with each other in that Indomethacin may decrease Coversyl's anti-hypertensive effect. It would thus be important to monitor Kate's blood pressure or alter her drug therapy.

It must also be noted that adherence is a complex behavioural process determined by several interacting factors. These include attributes of the patient, the patient's environment and the characteristics of the disease in question and its treatment.⁵ For instance, it was important for Kate* to alter her diet for both her hypertension and her rheumatoid arthritis. She did not, however, adhere to this aspect of her treatment.

Another significant fact is that not all patients have access to the same service and may not always be able to obtain drugs that are required by them. Time can also be viewed as a barrier to empowerment in health care. I found that it took at least half an hour to take Kate's medicine-history. This time is not always available in the public health sector. Rheumatoid Arthritis, as well as other chronic illnesses, are complex with differing individual needs attached to them. Sufficient time is therefore required in order to assess patients.

At this point it might be worth bearing in mind the gendered aspects of domestic life and their impact on coping with illness, given that other research has shown that women often put the health and well-being of others before that of themselves.^{7, 8} Kate*, a nursing sister at a nun's residence, does her own housework, and she also experiences early morning stiffness due to her rheumatoid arthritis. This is an example of how gendered aspects impact on coping with illness.

* name has been changed

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7K Reflection Statement

In dealing with patients suffering from a chronic illness it is important to find out as much information as possible on the patients understanding of their disease, medication and what their medicine taking behaviour is. It is our job as pharmacists to ensure that our patients are receiving the full therapeutic benefit of their medication to help us to help the patient we need to conduct a thorough interview on the patient with regard to the above mentioned, in order to compile a pharmaceutical care plan. This care plan helps us identify any drug related problems the patient may have at present or be at risk of developing.

Our interview went relatively smoothly, our patient had already been interviewed by another group and so she found no difficulty in understanding what we were trying to achieve and answering our questions to the best of her ability, so this was an advantage in a way, and a disadvantage because she could formulate her answers before the interview. She was very friendly and helpful in giving us full explanations to our questions and her answers. She was open and seemingly honest. She volunteered information we did not ask for and so gave us a full clear picture of her situation.

We both took turns asking the different questions and also asked questions not on the questionnaire. The interview was taped and we also took notes. In the beginning it was awkward but as the situation relaxed we felt free to modify our questions to her situation, to try to understand her point of view, beliefs and reasons for her behaviour. It was also important to try read between the lines, analyse the way she answered particular questions, what her body language communicated, the information she told us and the information she did not tell us. It was important to take note of how she described her relationships with her family and friends, especially with those members of her family who also have RA. To take note of how she spoke about the disease and what relationship she had with it.

Doing the interview was the easy part, it was taking all the information we had gathered and organizing it into a pharmaceutical care plan which was a bit more challenging, but this could help us see where the main problems were and what could possibly happen in the future. Because most of the history questions we asked were in the plan we asked her them directly, and it was just a matter of filling in the answers. With the review of systems we just had to observe the patient and include any ailments she had already pointed out to us such as her migraine and back pain.

She gave a full account of her medication history which was extremely helpful to us, not just in trying to understand what she had been through but it also gave us a deeper more real look at RA medication. The next stage was to take all the information on how she took her medication, what she thought of it and her other activities that might be important and analyse them to find any drug related problems.

Although we were not permitted in the interview to outline any drug related problems and counsel accordingly we had to include this in the PCP. Lastly we had to provide a monitoring plan for the patient. Taking the adverse drug reactions and drug-drug interactions and implement a correction of these, indicate the problems, indicate how to correct them and provide a follow up plan and possible interventions. It was interesting that with a seemingly -1 very compliant patient drug related problems especially interactions still manifested. Thus it was clearly seen how important it is to really take time in interviewing patients to gather all the information you can and then take action in drawing up a pharmaceutical care plan properly to identify drug related problems and take measures to try correct them. I found this exercise very helpful in many ways. Firstly it was the first private patient I have interviewed on their illness and so it was interesting to know her experience with health care in that area. It helped take our focus off just the clinical pharmacology and onto the patient and how their disease and medication affects them and their lives. It also highlighted how important our job of isolating drug related problems and correcting them really is. It would be great for all patients to realize the seriousness of their diseases and be so knowledgeable on their medication and life style modifications.

Appendix ‘H’

Course Evaluation



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6 August 2004

Dear Kevin

Evaluation Report: Pharmacy IV: Chronic Illness and Medicine Taking Behaviour Elective

I have analysed the student responses to the open-ended evaluation questionnaire for the Chronic Illness and Medicine Taking Behaviour Elective. Eight students responded to the questionnaire. My overall impression was that students found the course very valuable and thought that the course was well-structured and presented in a relaxed, interactive manner. The course challenged students' understanding of their role as pharmacists and their views of the nature of the pharmacist-patient relationship. They have gained a greater understanding of issues that impact medicine taking behaviour. The course has sensitised them to the role of language in pharmacist-patient interaction.

I have summarised their responses to each of the questions below.

What have you learned through participation in this course? If any of this was a new insight, please indicate this.

All the respondents have learned that the patient *experience* within the context of chronic illness was crucial and that pharmacists needed to take cognisance of this when developing patient care plans. Half of the respondents indicated that they have gained insights into the role of communication within the pharmacist-patient relationship. They have come to realise that people use words in different ways and that pharmacists need to be sensitive to the way patients use words and what that might indicate about how patients experience their condition and how they experience medicine taking. The course has enhanced their understanding of *concordance*, *compliance* and *adherence* in medicine taking behaviour. Three students indicated

that they have learned to develop a patient care plan, while two found the interviews with patients particularly valuable.

The Faculty has asked whether this course should be offered again in 2005 – what would your response be (please give reasons).

The students were unanimous in their view that the course should be offered again. An understanding of chronic illness and patient medicine taking behaviour within the context of chronic illness were vital for pharmacists given the increasing prevalence of chronic illness. The course offered perspectives on the role of pharmacists that were not dealt with in any other area of the Pharmacy curriculum. The following student's comment is worth noting, *"I felt (the course) was very interesting and very humbling – to stop regarding ourselves as future pharmacists as having power and control over the health of the public. I believe this course offers a new perspective as to the role of pharmacists, especially in the case of patients suffering from chronic illness...It offers valuable experiences and perspectives ... which we have not touched upon within ... this degree"*.

If the course were offered again, would you like it to be offered in the same way, or would you like to see changes? Please give reasons where appropriate.

One student indicated that the course should be offered unchanged. Two students thought that some aspects needed to stay the same, while others needed to change. Five students indicated that changes were required.

Students liked the relaxed, interactive style in which the course was presented. One student indicated that s/he liked the presentation and portfolio assessment and that s/he had learned *"much more long-term knowledge"* than s/he would have, if s/he had had to write an examination on the course material. Three students found it difficult to fit in the long journal articles every week, while another complained about having to access Moodle through the laboratories to get the journal readings. Three students thought that more patient contact / interviews would enhance the course. One suggested interviews with patients with different chronic illnesses would enhance the course.

I have included the raw data as an appendix to this report. Should you wish to discuss any aspect of this report with me, please do not hesitate to contact me.

Best wishes

Jo-Anne Vorster

Encl. 1

Pharmacy IV: Chronic Illness and Medicine Taking Behaviour Elective

Evaluation Data

What have you learned through your participation in this course? If any of this was a new insight, please indicate this.

New insights into chronic illness, compliance. Learnt about the new terms of adherence and concordance. Learnt in depth about Rheumatoid Arthritis and gained insight into what it is like to live with this disease. Learnt that words have connotations, i.e. one cannot take them at face value. This was definitely a new insight.

I have learnt the implications of a chronic disease to a patient. I have learnt that pharmacists have an important role to play in a chronic patient, and what this role is. I have learnt not to take what a patient says at face value, but rather to dig deeper.

This course was extremely valuable. It gave me a great understanding about chronic illness and chronic patients. I got better insight into how to deal with chronic patients and how to manage them. I got a great understanding of concordance, compliance and adherence which was very valuable. Interviewing an actual patient, with a chronic illness was great. It was very good experience and I learnt a lot from this. Also very interesting and enjoyable.

Most importantly, I learnt how to distinguish between what we as health care givers may perceive an illness to be, vs. how a patient may experience this illness. This difference emphasized the need for concordance in establishing a health care regimen for a patient, to attempt to influence adherence. The course incorporated all forms of chronic illness, not just Rheumatoid Arthritis, but I did feel that I am now more aware and knowledgeable regarding RA drugs, their indications and side effects. Not only did we focus on the use of language and empathy in conversation with the patient, we established that words used – within their context or intent – may be interpreted differently by another, and the impact this has on the mind, attitude and opinions.

How concordance works; comparison between concordance, adherence and compliance, gave me deep insight on how to improve patient quality of life. Conducting interview on real patient, gives the opportunity to experience what one can expect as a pharmacist in real life. How to present reports and to discuss the findings.

I have learnt to take the whole person into account when designing pharmaceutical care plans. Also learnt about meanings of “words” to patients.

That chronic illness is so far very different to any other illness, it needs a different approach and complete participation of the patient. There is disparity between understanding between the health professional and patients. To achieve common understanding there should be compromises from both parties.

I learnt how to practically apply my knowledge and actually put a care plan together and link a person's experiences, knowledge and understanding to mine and try to bridge that gap and try to help them at their level. Updating my compliance knowledge to a better way of thinking and working with patients to really improve therapeutic outcomes. This is definitely a new insight.

The Faculty has asked whether this course should be offered again in 2005 – what would your response be (please give reasons).

I would agree with the Faculty. It has been very valuable in teaching me about chronic illness and how to look at things from a patient's point of view. The readings we were given were valuable in learning more about compliance in patients. The course was enjoyable because it did not have a normal lecture format – it was a nice informal change.

I think that it should definitely be offered again in 2005. Understanding chronic behaviour, and knowing how to help patients with their medicine taking is important in helping patients through their chronic disease. Building a concordant relationship with patients and helping them to be adherent is an important role for pharmacists, especially with the increasing prevalence of chronic illness.

Yes, it should definitely be given next year, because as Pharmacy students, it gives the understanding of disease and illness from a social and psychological perspective.

Yes, I do agree that this course should be offered again. I felt it was very interesting and very humbling – to stop regarding ourselves as future pharmacists as having power and control over the health of the public. I believe this course offers a new perspective as to the role of pharmacists, especially in the case of patients suffering from chronic illness, of which we can deliver into the old, traditional role. This course, I believe, runs concurrently with our Pharm Admin and Practice course – especially pertaining to the Community Experience Programme. It offers valid and valuable experiences and perspectives of which we have not touched upon within the fields of this degree.

It should be offered next year if possible. This course emphasizes what we have been learning in theory. It is more of reality than theory. Compared to other electives, I think this is the most productive. By the end of the course, I have something to be proud of. It is a wonderful course.

Yes. It gives students a new perspective on patient care. It teaches students to look at disease in a social context. Lastly, this is an interactive and fun course.

It is very important and eye opening. I think almost every Pharmacy student should do this course. It sets foundation as to how to deal with individual patients, how important are words said by the patient and their different meanings to the health professional.

I definitely think it should be offered again, as it brings the whole compliance issue up to date. It offers a different look at an aspect of pharmacy which I found was so important and hasn't been touched on in any of our subjects. It's very practical and aids in our understanding of our role as pharmacists. I really enjoyed this elective, I feel it will help me in my future and I learnt a lot.

If the course were offered again what would you like to see: (A – should be offered unchanged; B - Should be offered, with certain changes; C – should not be offered again.)

B

A

A, B

B

B

B

B

A, B

Please give reasons where appropriate.

Perhaps have more patient contact and thus get to see the real life situation rather than reading a journal article about a patient.

None given

Kept as is with regard to its structure. Change: Moodle system is great, but going up and down to labs can be very inconvenient.

The course was brilliant and well constructed, but I am sad to say that as much as I tried, I could not keep up with all those journal readings. While I do not deny that upon reading them, I did feel that they helped and shall use them to a great extent within my portfolio – I was unable to read them (properly) before each lecture. Please understand that we do accept and attempt to master time management – but we need to deliver a certain amount of time to each subject regarding 'credits'. The feedback we could give on Moodle was understandable and appreciated and shall help toward portfolios, but time is given to the thoughts there ... and then still to read for an hour ... and this all late at night because practicals all afternoon or computer labs only available at night, and then the hour or so devoted to our major subjects! ...I do not want it to seem that this course was not appreciated for what it is worth – I really did learn a lot but struggled to meet all the reading deadlines. Between a Monday to Friday, weekends are the only time we may be able to even begin to think of our extra credits.

Some changes need to be done, from my point of view, it is more sociology than pharmacy, the two need to be assimilated together. Conduct more interviews, e.g. instead of one patient, should be two if possible, so that when presenting the overall result, one should not be very biased about patient behaviour and medicine taking.

I think that interviewing only one patient with just one chronic disease is not enough to learn about chronic illness. More patients with different types of diseases should be interviewed. The film “Wit” made an impact on me.

All students need to be equipped with information on how to relate with chronic patients. Should be part of PAP, not as an elective. It was a good elective course. Thanks.

Open discussion type lectures – relaxed atmosphere.

Moodle – liked the access to articles, ability to answer questions and get replies; the whole interactive learning is great.

Having presentations and a portfolio rather than an exam – learnt to much more long-term knowledge.

What should be changed – Some of the articles were really difficult to understand and really long – maybe just sections (relevant) could be highlighted to read.

Appendix 'I'

Journal Entry 6: Reflection on 'Wit'

1A Last edited: Wednesday, 26 May 2004, 05:22 PM

Prof Bearing, Prof Kalekian and Dr Postner all had the similarity in the sense that knowledge was very important to all of them. They were all academics and we know that Prof Bearing was quite renowned in her field of academics. It can be assumed that Prof Kalekian was also top in his field and his research meant a lot to him. He had a thirst for knowledge and was definitely looking for a breakthrough. Dr Postner, gave the impression that he was quite knowledgeable and he definitely had a passion for research. This excited him and this came across when he was talking to Vivian about his research, specifically when he was going on about how marvellous cancer is, in terms of research, and it did not occur to him horrendous cancer is to a patient.

As the film progressed, there was a great change in Prof Bearing's attitude and to a certain extent her thinking. Being someone, whose whole life was based around her academic career, which was so important to her, the illness and time in hospital changed her a lot. In a sense, Vivian became more humane, she began to feel and understand people's feelings. She understood this because of the way she was treated by the health professionals (Kalekian and Jason) in the hospital who had no care for her as a person but she was only important to them as research. Vivian looked back with regret at the way she treated her own students. She was so stern and strict with them and only worried about her work, she never took the time to understand them or never was easy on them. She realised that she was just like Jason and Kalekian in a sense in her own academic sphere, so she could understand their attitude towards her. But now her attitude was changing, she was just looking for some empathy and care from Dr. Postner and Kalekian, she just wanted to be treated like a person not like a research entity. She realised that knowledge was not everything and meant nothing, especially if there was no humanity, care and empathy to go with it.

Not much change is noticed in Prof Kalekian or Dr Postner as the film progressed. To both of them, their research comes first and that impression is portrayed throughout the film.

2. Values, Attitudes and Communication of the Medical Professionals

Dr Kalekian: Throughout the film, it was portrayed that research was most important to him. He did not really care about the patient (Vivian) and what she was going through. He did not communicate much with Vivian during her treatment, (apart from ask how she's feeling, which did not sound very sincere) in the sense explain much about her treatment or procedures. He assumed that this was un-important and probably not necessary. Whenever he spoke to Vivian or around her, about her therapy, he communicated mostly using scientific jargon, which Vivian did not

understand. He also was never really reassuring.

Dr Postner: To him, this was all about research. He came across as very arrogant. He behaved in a way he believed was professional. When he interviewed Vivian to take her patient history, he came across as distant, uncomfortable, quick, displayed no eye contact and as the film progresses one can get the feeling that he is not a people's person and that he does not like people very much. Dr. Postner in terms of his values, I would say that he did not respect people very much and their feelings. When Vivian had made her decision that she did not want to be resuscitated, Jason did not respect that and had to be stopped forcefully by Suzie. Jason also did not care about the patient or did not even begin to try to understand what the patient was going through. Suzie: She was very different, she displayed empathy towards the patient, she was caring and understanding. She checked on Vivian, was there for Vivian when she needed someone and was concerned about her treatment. She could see what the treatment was doing to her. She was very genuine.

3. The diagnosis announcement made by Dr. Kalekian was non-emotional. He used scientific language to explain Vivian's diagnosis to her which she did not understand and he did not realise that she did not understand what he was saying, although she said she did. He came across as very tough and to a certain extent you could see that he was happy that she had this cancer because it was good for his research. He made Vivian sign consent to the treatment in a way that was not really acceptable, because she did not understand what the treatment was about or what she was in for. That is not something a doctor should really do and was not a manner of getting consent. In the scenario where Dr. Kalekian announces the diagnosis and throughout the film as well, he knows the power is in his hands because he has the clinical knowledge and Vivian was dependant on him. It never really occurred to him that he was just as dependant on Vivian, for his research. Dr. Kalekian uses this power he has over Vivian to make her sign the consent form, which demonstrated very unethical behaviour.

The scene involving the examination done by Dr. Postner, showed Jason as an arrogant health professional, this was demonstrated when he stormed out of the room to get a nurse because it was part of the rules. He handled Vivian roughly. He did not know how to go about treating a patient during an examination of that nature, in other words he had no "bedside manner." He was very uncomfortable and unsure as to how to go about the procedure. He behaved in a way he believed was professional. Also he stripped the patient of all her dignity and Vivian felt violated. His mannerism was appalling but he actually did not realise this.

4. The scene with Susie and Vivian involving the popsicle, illustrated Susie's empathy and care. Vivian felt comfortable around Susie, trusted her and could admit her fears to her and express her feelings. Vivian was a very tough and strong person, not emotional and did not really express her feelings. In this scene, when Vivian was in her last stages and could not bear it anymore or hide her feelings, she felt sure she could express herself to Susie. Susie encouraged her and allowed her to express her feelings and fears. Susie understood what Vivian was going through and how sick the treatment was making her.

She was prepared to be there for Vivian at anytime and she did just that. Vivian had come to like Susie, that is why she offered Susie the popsicle and she also wanted Susie to be with her at that time. In this scene, Susie uses this opportunity to tell Vivian what her choices are, and that she needs to make a decision. Susie respects her choice and more importantly understands it.

2L Last edited: Tuesday, 4 May 2004, 10:20 AM

1. At the beginning of the film these three characters are very similar in their attitudes towards life. They all seem to lack a degree of humanity when it comes to dealing with other people. As the film progresses Prof Bearing comes to this realisation as she is now the subject of such treatment and attitudes. Throughout the film Prof Kelekian and Dr Posner remain aloof without showing much emotion.
2. From this film it is evident that the values of the medical profession do not lie with helping the patient but rather with their own interests. This film shows that the medical practitioners regarded their patients as objects or a disease and not as individual people. There is a distinct lack in communication between the doctors and their patients as they do not feel it necessary to develop any kind of relationship with them.
3. From these incidents it is evident that the doctors do not consider the feelings of the patient relevant and see her as purely a research project. When Dr Posner is Examining Prof Bearing he does not show any sympathy to what she is going through but rather puts across the attitude that he doesn't have time for this and would rather not be there. Throughout the film there is a lack of understanding and sympathy expressed by the doctors.
4. This incident showed a totally contrasting view of the health profession as here the nurse actually showed concern for the patient and wanted to know what it was she wanted and how she felt. The nurse was not interested in her as a research project but as a person to be cared for and looked after in her final days.

3C Last edited: Sunday, 25 April 2004, 01:50 PM

1. The professors (Prof Bearing and Prof Kelekian), in my opinion, are intended to appear very similar to each other at the beginning of the film- in the sense that they are both highly 'intellectual' and highly regarded in their professions. The professors are attempting to treat each other on the same level- with a very 'distant' approach to humanity, focusing on medical jargon or words and terms to experience the illness as a 'thing'- to be studied- rather than as a personal disease, affecting Prof Bearings life. Throughout the 'flash-back' scenes regarding Prof Bearings life, we are reminded that this is how she treated students or dealt with life in general. As the first scene progresses, we start to feel the uncertainty in Prof Bearing, as she starts to slowly lose power in the conversation, and finds herself submissive to what Prof Kelekian has to say. She is now put at a level where she no longer has control as she has to listen to the terms used by Prof Kelekian, and handles this new situation with her wit, yet inability to admit defeat. It is only as the movie continues that we observe differences in their characters, as Prof

Bearing starts to observe and understand the lack of empathy and human understanding that Prof Kelekian offers as a medical care giver, and relates it to her own profession. Prof Bearing starts to realise that human contact and empathy is a necessity in the world. As Prof Bearing grows in this understanding and expectation of her care givers, Prof Kelekian is portrayed as the same, 'cold' attitude toward his patients- and even as time has given them a chance to get to know each other, he is never able to relate to her as a human with emotional pain.

Dr Posner as an intern, under Prof Kelekian, is seen to be very uncomfortable in the scene regarding the medical examination, and attempts to cover up his discomfort through the use of medical jargon/terms. He attempts to make the situation appear routine and formal, so as not to reach too close or intimate contact with his old professor, and the professor as a woman. This discomfort also leads to his uncertainty as he clumsily attempts to get ready for the procedures. Dr Posner is characterized as a younger version of Prof Kelekian, and we observe their similarities throughout the film as Dr Posner attempts to meet the expectations of, and impress his mentor, Prof Kelekian. Dr Posner does not grow in affection or in his attitude toward Prof Bearing, showing little empathy and hiding from uncomfortable situations through his knowledge of medicine and the body.

2. This film portrays the doctors (including Prof Kelekian and Dr Posner, as well as interns) as observing medical situations as a research opportunity, rather than a disease to the human subject- a disease affecting the person physically and emotionally. Little VALUE is placed on human life or care, with the emphasis on the disease as an entity. They derive their value from an understanding and appreciation of the disease entity. The nurse (Sister Susie), however, attempts to improve the quality of life of the person suffering. The value she places on medical situations is that quality of human life is more important than quantity; per se. Suzie values the dignity of human life and attempts to offer this to her patients, regardless of their illness.

The ATTITUDES of the doctors is to 'get the job done', to find a cure or to alleviate symptoms- not necessarily for the benefit of the patient, but as a contribution to science. The understanding of which, will help them progress as doctors and the profession in recognition. They regard themselves as the knowledgeable and powerful characters to a subordinate patient with intellect not as vast as their own. The attitude as observed in Suzie as a nurse is that the patient is still a human, with knowledge and experiences which may far outweigh her own, and these are held true to her and to the patient. She offers the patient a respect and dignity as a human, indicating an understanding of difficult situations the patient might find themselves in, offering an empathetic attitude that while they may have an embarrassing problem (such as vomiting by Prof Bearing), that she is there to help them through it without judgment.

The COMMUNICATON throughout the film was clearly indicated as medical jargon as offered by the doctors. This left the doctor in control of the situation, without necessarily having to explain the problem to the patient, as the patient merely accepted terms being thrown at them. Little eye contact is made with the patient, with scenes such as 'ward rounds' indicating no connection to the human and the disease being of a whole, rather the disease is 'spoken to' and spoken of. Dr Posner treats the 'history taking' and medical

examination with little interest, reading through it fast as though it is a routine of which he does not feel he should be subjected to. He is not interested in what a patient has to say, rather avoiding personal contact where possible and where conversation is required: "How are you feeling today", asked with little care and disregard for how the patient actually feels. Dr Posner does not feel it necessary or sees it as a waste of time, to offer the patient an explanation regarding the disease or treatment. Sister Suzie on the other hand, openly communicates with the patient, and brings medical terms down to a level of understanding that the patient regards as acceptable. She offers sincere questions into the well being of the patient, and speaks to the patient so as to encourage conversation and feedback- such as the 'popsicle scene'. Before Suzie starts with a procedure or as she is working, she explains to the patient what is happening or why a certain procedure is being conducted, to offer the patient a better understanding of her treatment and the disease. Where she feels the patient is 'in the dark' regarding a subject, she openly discusses this with a patient, allowing the patient to know that their decisions and opinions regarding treatment are important.

3. In the scene where Prof Bearing is given the diagnosis, Prof Kelekian takes on a serious and 'no nonsense' role, immediately offering terms and explanations of medical jargon. His communication style here is one to show his intellect and understanding of the disease, with an attitude expressing his dominant power in the conversation. He does not expect a response from Prof Bearing, but merely that she should accept what he has to say. Where he asks if she understands or if he is going too fast, it is not out of concern, but more out of routine and 'taking in' the power he is exerting over the situation. As he speaks faster and more verbose, the excitement builds up in his voice, indicating the value he is placing on Prof Bearing's cancer as an invaluable contribution to science and the profession. Prof Kelekian offers little time or concern that Prof Bearing should understand her problem or the treatment, with no indication of empathy toward the impact that this cancer should have on her life.

Dr Posner (as discussed in question 2) communicates with people behind the 'screen' of his medical profession. He uses medical jargon to hide his discomfort in a personal contact situation, and treats an interview as a routine of which he feels should not be a requirement within his capacity as a doctor. He attempts to appear what he believes as personal, and does not extend above this. Dr Posner offers little eye contact during the medical interview, reading through the questions very fast, with little interest in the answers and with little time for this unnecessary procedure, and any wit Prof Bearing may attempt to overcome her own discomfort. Human dignity holds little value to Dr Posner, where it appears dignity is lost to him as the patient becomes an object of research. The value and quality of life seems an obstacle in the way of Dr Posners ultimate desire to study and work on the disease, hence he offers little explanation as to what and why he is doing something.

4. As discussed in the previous questions, the situation between Susie and Prof Bearing is indicative of empathy and value to human quality of life. The 'popsicle scene' is an opportunity to observe both the understanding Prof Bearing has started to develop regarding human interaction and the important role Susie plays as a care giver. Suzie shows sincere concern when she enters the room when Prof Bearing is experiencing intense pain. As Prof Bearing offers Suzie the second Popsicle, one notes her opening

toward and desire for human understanding and interaction. Suzie stimulates a open and warm conversation by bringing up a story from when she was younger, this tones the intensity of the pain down for Prof Bearing as she opens to what Suzie has to say. Suzie speaks genuinely out of concern to Prof Bearing as the realization has come forward that Prof Bearing will die soon. Through initiating the topic of resuscitation, Suzie will have confirmed her knowledge as a medical care giver and that of what Prof Bearing is experiencing- without in as much words as to make it too direct that Prof Bearing is nearing death. Suzie indicates that she wants Prof Bearing to have a fair say and decision regarding her own life and dignity of her body, and explains procedures and terms as the doctors may attempt to explain to her. The value and attitude toward human life as offered by Suzie, allows Prof Bearing an opportunity to think about herself as a person, rather than as a person with a disease.

4L Last edited: Thursday, 29 April 2004, 03:57 PM

1.The three Prof Bearing, Prof Kelekian and Dr Posner are totally different,Dr Posner tries his best to resemble his medical teacher Prof Kelekian, in the medical arena Prof Bearing is not regarded as her tittle mean, She is not in the same ground with her doctors and treated like a learning object for experience. The first interaction between Prof Bearing and Prof Kelekian shows that Kelekian does not consider her as an elite in the medical area, only when his interest is expressed that he seem to understand that she is an elite.As the film goes on the interest(experimental) predominate and the element of patient-doctor relationship is totally lost. 2.The medical professionals as exmplified in the film have no respect to personal morals, do not value patient interpersonal believes. They are very very poor communicators both verbally and non-verbally. 3.Communication is very poor,there is no confidance,the patient is maltreated,not even informed of what to be done to her. There is sigh of concern that could not be hidden, but what dominates is pretending every thing is occur. 4.Susie showed concern,empathy and became friendly,she came to the patient level, explained what was/were to have been explained by the doctors,She gave a helping hand and explained some of the adverse effects the patient were expiriencing. Though seemed to be busy she created time to sit and chat with the patient.

5A Last edited: Monday, 10 May 2004, 10:15 AM

1.)They had very similar personalities and values in life. All three are intellectuals who value learning and information more than anything else in their lives. In a sense they are on the same level when the film begins, a level that few people are on, a level of academics and science with little feeling and emotion in their lives.

2.)Their values are centered around the importance of research to them. They have very cold attitudes and their communication skills emphasise this. There is a severe lack of human warmth seen by them, little understanding to what she is going through. They value her as a breakthrough in their research.

3.)I would say the same thing, there was no patient care, she was treated as an object for

research. Jason was always very professional, too professional, but then so was she. I think Jason was also intimidated by her because of her career and knowledge and that added to his lack of empathy.

4.) Suzie showed real patient care and empathy. She was human, whereas the others almost seemed like robots the way they carried out their examinations. Suzie was warm and valued the feelings of others and communicated gently.

6F Last edited: Wednesday, 21 April 2004, 11:46 AM

1. Prof Kalekian and Prof Bearing were similar in that they were both educated scholars. They were also relatively un-emotional with relation to the work they did. Dr Posner was just as unemotional. However, he was not comfortable with people, which was quite evident, while the other 2 characters were. As the film progressed, Prof Bearing became 'dependant' on Prof Kalekian's knowledge to defeat the cancer. Also, she did not receive the emotion and care that she needed from these two men, the emotion that she had not shown anyone for most of her life. Also, as the film progressed, Dr Posner's confidence with regard to his work became more evident.

2. Health Care Professionals are in the people profession, yet they seem to avoid the communication that is required. For example, they always seem to ask th Prog Bearing how she's doing, as though it's an after-thought, but almost never pay attention to the answer. Also, there is almost never an explanation to Prof Bearing the procedure they would be conducting on her. They treat patients as objects rather than people and they value increasing their professional status more than helping people. Suzie (the nurse) on the other hand, is the model of a health care professional. She not only respected Prof Bearing, but she also respected her patients rights. Suzie also took time to show Prof Bearing empathy and emotion when she needed it the most.

3. Dr Posner was very unprofessional in this scene, and failed to explain to Prof Bearing the procedure he was about to perform. This added to the uncomfortableness felt by all parties in this scene.

4. Suzie communicated with her patient, paid attention to her needs, and most of all, showed her empathy when she needed it the most.

7K Last edited: Monday, 3 May 2004, 10:18 AM

1. Prof. Bearing and Prof Kelekian were quite similar in the beginning with regards to their dedication to their work and not their patient/student, as you see in the opening scene and when Vivian refers back to her teaching.

At the end they are very much different, Prof Kelekian still has no relationship with his patient and only sees her as a research project , wheras Vivian has realised the importance of relationships especially caring ones.

Dr Posner is different from her in the beginning and gets worse really, although he made

his intentions clear from the start that dealing with patients was only a means to an end, his main concern is with research , at the beginning he is unsure of himself and nervous, but by the end he is similar to Prof. Kelekian gaining the same attitude to his patients as his mentor has.

2. The medical professionals in this film convey, that they value their research work more than the patients they treat, they do not value caring relationships and taking an interest in how their patient is really doing. Their communication is one way and in their terms and expressions, they do not really listen and so do not really communicate interpersonally, but through tests, and results. They lack genuine concern for their patient's well being.

3. Prof. Kelekian was clinical in his diagnosis, he explained in his terms, he was excited about her cancer and being able to treat her as part of his research, He lacked any caring concern for her and what she was about to go through and was very factual.

--> Still to be finished -- battling with how to express the attitudes?

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The ☺ symbol to the left of an entry indicates that this resource is available on the enclosed CD under the folder 'Readings'. The principal author's name and publication date have been used as filename. Where possible, readings to which access is difficult or where pagination may differ between online and downloaded versions, have been placed on the CD. Since HTML documents frequently do not have page numbers, where page numbers are given they assume a printed version of this document using a browser print facility set up for an A4 portrait page size.

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