AN INVESTIGATION INTO CULTURAL DIFFERENCES IN THE CONCEPTUALIZATION OF AND ATTRIBUTIONS ABOUT COGNITIVE DECLINE IN THE ELDERLY

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DAVID ALAN FAIR

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DECLARATION

I hereby declare that the work contained in this thesis was carried out by myself, under the supervision and guidance of **Cora de Villiers (MA)** and **Professor D.J.A Edwards.**

This thesis has never been submitted for a degree at any other University.

David A Fair

Dated: 10th day of December, 1999

DEDICATION

To my parents, Arnold and Iris Fair
for their fluctuating, though impassioned,
support for this project

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I would like to thank Cora de Villiers for her guidance and generosity during the early phases of this thesis, and for granting me access to her Langa data.

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My MA class mates for providing me the opportunity to suffer in numbers.

ABSTRACT

There is little data regarding the prevalence of dementia in South Africa. Estimating such prevalence is problematic as the most commonly used cognitive screening tests are inappropriate for use in non-western populations. For this reason researchers have explored the use of informant questionnaires where relatives provide information on cognitive functioning over the last year. In the South African context Lenger, de Villiers & Louw (1996) conducted a dementia case-ascertainment study in a Xhosa-speaking community near Cape Town using a well-known informant questionnaire, the DECO, and concurrent clinical assessment. Reflecting on the discrepancies between DECO scores and clinical diagnosis, the researchers conducted interviews to explore beliefs and expectations regarding the elderly and cognitive decline. The aims of the current research were to gather comparative data from Bothasig, an English-speaking community, in order to explore areas of commonality and difference in perceptions and attributions regarding cognitive decline in the elderly. The study found that a significant percentage of informants from both Bothasig and Langa consider forgetfulness to be normal in old age. Different discourses around illness in the elderly were identified incorporating a range of medicalised and folk attributions. The discussion showed that informant perceptions within the Langa community may increase the likelihood that observational data provided in informant questionnaires may be confounded by cultural perceptions regarding the elderly. In addition, certain items on the DECO were found to be unsuitable for use across groups and modifications were proposed. The data was analyzed using both quantitative methods and phenomenological discourse analysis. The discussion concluded with metatheoretical reflections on the tension between etic and emic perspectives in cross-cultural research.

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CHAPTER 1: INTRODUCTION - RATIONALE FOR THE STUDY

Dementia is a neurological disorder reflected in a widespread dissolution of mental capabilities and social functions. The most commonly diagnosed dementia is Alzheimer's Disease (AD). The prevalence and epidemiology of AD has been extensively researched worldwide, although no such studies have been conducted in South Africa. Informal investigations among clinicians throughout the country suggest, though, that Alzheimer's disease is underreported in the black population.

In an effort to establish preliminary estimates of the prevalence of dementia in South Africa, a pilot study has been conducted with a cohort of patients from Langa, a black community outside Cape Town (Lenger, de Villiers & Louw, 1996).

Given the limitations of cognitive-style screening instruments, interest has been generated by the use of Informant Questionnaires, whereby a relative of the elderly person provides information on cognitive functioning over the past year. A promising informant questionnaire, the DECO (Détérioration Cognitive Observée; Ritchie & Fuhrer, 1992), appears to offer the possibility of being developed into a viable dementia screening instrument for the heterogeneous South African population, although certain problems were evident when it was piloted on the Langa participants. The agreement rate between the DECO and the "gold standard" (clinicians' diagnosis)

was 67%. This discrepancy is too large for the DECO to be used further without being modified.

The relatively high rate of false positive diagnoses indicates that certain informants answer in the ‘severe’ category too frequently for an individual that the gold standard indicated was in fact not dementing. Why then the misobservation by these respondents? The researchers hypothesized that the informant beliefs regarding old people, forgetfulness, and dementia are erroneous, and thus affected what they observed. Moreover, certain items on the DECO where found to be culturally inappropriate for use with the Langa participants due to their poor discriminability.

This study aims then to examine cultural beliefs around forgetfulness and cognitive decline in the elderly among the Langa informants, and then to compare these perceptions with those drawn from Bothasig, a lower middle-class white community outside Cape Town. The value of a comparison group is that it can be established whether similar beliefs are present in a group from a different educational and cultural background. Are these beliefs peculiar to the Langa group, or are the Bothasig group also likely to answer with a low discriminability rate to the IQ?

Thus, reflecting on the high rate of false positives, it was hypothesized that the informants’ responses were affected by their beliefs around old age and associated forgetfulness. In addition, certain DECO items were found to contain inappropriate

concepts or language for the Langa population. It was thus apparent that a follow-up study was needed to (a) modify certain key DECO items so that the questions were phrased in appropriate language using suitable concepts, and (b) explore the attitudes and beliefs within the Langa population to determine whether cultural factors influenced observations. Since the eventual aim of the project was the creation of a standardised informant questionnaire for cross-cultural screening purposes, the Bothasig comparison group was selected to allow this researcher to determine:

- whether beliefs and attitudes regarding old age and forgetfulness differ according to area, cultural background or any other factors.

- whether perceptions and understandings of dementia differ between the Bothasig and Langa groups.

- whether informants reported the same key concerns, or noticed the same objects of forgetfulness across the two groups. These data will allow certain key items of the DECO - identified as problematic in the Langa study - to be modified for use across both groups. Further validation studies may then be commenced.

This study thus pursues the dual aims of elucidating culturally-based perceptions of cognitive impairment in the elderly, and then using this information to examine the

viability of adapting the DECO informant questionnaire for dementia screening in South Africa.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

Dementia is a disorder characterized by the development of multiple cognitive deficits including memory loss and disturbances of executive functioning (American Psychiatric Association 1996). Alzheimer's Disease (AD), the most common of the dementias, is further characterized by gradual onset, progressive degenerative nerve cell changes, and concomitant progressive global deterioration of intellect and personality (Lezak, 1995). The prevalence of dementia doubles every five years in individuals between the ages of 65 and 85 (Terry, Katzman & Bick, 1994).

Current estimates indicate that, by the year 2035, 7% of the South African population will be aged 65 or over, a significant increase over the current level of 4.3% (Eckley,1994). Given that unprecedented growth is expected in the 80+ age group, health professionals can anticipate a great increase in the number of cognitively impaired elderly.

It is thus crucial for accurate and applicable screening measures to be available, both for the purposes of epidemiology, which is necessary for the planning of health services, and for the purposes of early detection, which assists both caregivers and health professionals in sensitive and astute management of dementia sufferers. In this

regard, a plethora of epidemiological research has documented the prevalence of AD in many countries world wide. However, there is a paucity of published reports on the prevalence of dementia with regard to developing countries (Rajkumar, Kumar & Thara, 1997). No epidemiological study has yet been conducted in South Africa.

2.1.1 Prevalence of dementia

Although the prevalence of AD is unknown in South Africa, evidence suggests that this diagnosis is only rarely made in black South Africans. Three reasons can be proposed to account for the low incidence and unknown prevalence of AD among black South Africans:

- The first proposed reason is that life expectancy among the black South African population is lower than that of the white population. Available figures show that 8.7% of the white population are 65 years or older, while the percentage of elderly black people is 3% (Prinsloo, 1991). By the year 2030 however, a projected 5.5% of the black population will be elderly.

- The second proposed explanation involves the cognitive measures used for screening and diagnosis of dementia. Since there are no reliable biological markers for late-onset dementia, cognitive screening tests have been used by researchers and clinicians. Although these tests have demonstrable reliability and validity when used

with middle-class literate populations, their use is problematic when applied to uneducated or illiterate people. Widely used tests such as the Mini-Mental State Examination (MMSE) test specific cognitive skills acquired through years of formal schooling. The MMSE has been shown repeatedly to misclassify illiterate people.

- The third hypothesis to account for the low prevalence of AD in South Africa involves cultural perceptions regarding cognitive deficits in the elderly. Colloquail evidence suggests that memory difficulties may be considered evidence of normal aging. Cultural factors among black South Africans may also result in a reduced tendency to pathologize dementia symptoms and thus people exhibiting such symptoms may not be brought to the attention of health care workers.

In spite of such perceptions it should be noted that age associated memory impairment, that is, memory impairment not associated with a disease process such as dementia, is an *abnormal* condition, occurring in only 38% of the population, according to one estimate (Larrabee & McEntee, 1995). Estimating the prevalence of age-associated memory impairment is, however, a vexed topic, presenting epidemiologists with difficult methodological challenges and consequently several studies have produced conflicting estimates (Larrabee & Crook, 1994).

Nevertheless, the confounding effects of cultural perceptions regarding memory impairments and dementia have been demonstrated in cultures world wide.

2.2 Culture and perceptions of dementia

From the empirical standpoint of western medicine, the dementias represent a well circumscribed, objectively verifiable group of conditions that are independent of such subjective factors as culture and individual interpretations. However, a survey of cultural perspectives regarding dementia reveals that these subjectively constructed factors have an important role to play in both understanding and diagnosing dementia. Research indicates that different culturally specific discourses of dementia exist worldwide, and that members of these cultures define, understand and react to dementia in distinct ways. The following section will introduce the concepts of 'emic-etic' research, which serves as a useful framework for understanding the relationship between medical definitions of dementia on one hand, and culturally shaped understandings on the other.

2.2.1 The Emic-Etic distinction in cross-cultural research

Cross-cultural studies may be approached from two different perspectives, which, together, have been referred to as the 'emic-etic distinction' (Berry, 1989; Brislin, 1990). The 'emic' perspective entails evaluating phenomena from within a culture (culture-specific), while the 'etic' perspective aims at establishing overarching categories of phenomena (culture-general) in order to identify and compare equivalent

phenomena across different cultural contexts (Canino, Lewis-Fernandez & Bravo, 1997).

The distinction between the 'emic-etic paradigm' relates closely to the difference between 'universalist' and 'relativist' approaches (Swartz, 1998). In psychological research, the universalist approach is typified by the use of a single diagnostic system - the DSM IV - for use across cultures. This approach has been criticized for reifying mental illnesses by seeing nosological categories as equally valid regardless of the cultural population under study. Thus, while universalist/etic approaches have the benefit of facilitating cross-cultural comparisons, there are serious limitations. Universalist methods tend to obscure cultural differences and lose important cultural information as indigenous categories of illness are "pruned" to conform with DSM IV categories (Ensink & Robertson, 1997). Crucially, universalist approaches do not allow for an understanding of how the socio-cultural context shapes illness definition and symptom expression. This limitation has particular import when viewing dementia cross-culturally.

In contrast to the fundamentally 'etic' perspective of universalism, relativism adopts an 'emic' perspective by seeing culture as inextricably bound up with the phenomena under study. The following section will survey a body of research that demonstrates the merits of adopting an emic/relativist perspective in documenting and understanding

dementia cross-culturally. Such research is invaluable in revealing cultural variability regarding behaviours and symptoms associated with dementia.

2.2.2 Relativist contributions to understanding cross-cultural manifestations of dementia

Smith (1996), in his overview of cross-cultural research on AD, criticized the assumption that the "criteria embedded in diagnostic instruments reflect a pathology that can be universally identified irrespective of cultural context" (1996, p. 256). He stated that local interpretations of disease have the potential for affecting prevalence estimates for dementia. Moreover, the author noted that cultural variables can effect the *expression* of disease. Smith wrote that in the case of Alzheimer's disease "these modalities can pattern the expression of symptoms of cognitive decline in ways that may not be assessed accurately by epidemiological instruments originally normed on Anglo-Saxon populations" (1996, p. 256). The implication of this perspective is not that available screening techniques should be seen as untenable, but rather that "the translation of diagnostic instruments should…be preceded by extensive ethnographic accounts of how members of targeted cultures interpret disease and categorize symptoms…" (1996, p. 256).

In China, cultural beliefs around dementia significantly influence caregiver's mode of identifying and attributing symptoms of cognitive decline. Ikels (1998) discovered that

many of the behavioural changes associated with dementia are frequently considered normal and an inevitable concomitant of old age. For example, there is a traditional Chinese belief that people in old age return to a 'childish state' and become 'clumsy'. Furthermore, even strange public behaviour may be excused on the grounds of childishness. Interestingly Pollitt (1997) similarly recorded that among Australian Aboriginal people, mild to moderate dementia may be seen as 'childlike behaviour'. Chinese caregivers are also unlikely to employ a medical model to account for dementia, instead drawing on traditional beliefs such as an imbalance between opposing forms of energy or retribution for the sins of one's ancestors (Ikels, 1998). Beliefs such as these significantly reduce the likelihood that dementia sufferers will be brought to the attention of health care workers.

Examining the impact of culture on the cognitive structure of the perceptions of illness, Angel and Thoits found that "cultural influences on the perception and reporting of health status have practical implications for the cross-cultural study of the incidence and prevalence of disease" (1987, p. 466). Furthermore the authors note that "The phenomenology and cognitive equivalence of such reports across groups which differ in culture and socio-economic status…[means that] one must understand the meaning-shaping vocabularies and cognitive structures through which perceptions are filtered" (1987, p. 467).

Cohen (1995) conducted an enthographic study exploring the "heuristics of senility" among the Banaras of India. The author found that "definitions of dementia in Banaras span overlapping explanatory realms about brain function and behaviour that would be inadequately represented by current neurological models" (1995, p. 332). Work on establishing the prevalence of dementia in rural India has encountered a similar phenomenon: "…community expectations of the elderly are low and thus many potentially treatable sources of disability, including memory loss, are unrecognized or tolerated as part of normal ageing" (Rajkumar, Kumar & Thara, 1997, p. 705).

Pollitt's (1997) overview of the problem of dementia among Australian Aborigines demonstrated that indigenous views of abnormality do not necessarily fit western conceptual frameworks. His study revealed that not only in there no equivalent term for "dementia" among Aboriginal people, but that behavioural characteristics of severe dementia may be seen as "madness". In addition "the thresholds between 'sickness' and 'madness', or 'normality' and 'abnormality', will vary between communities" (1997, p. 158). Pollitt's survey highlighted the failure of certain cognitive screening tools as having a limited application due to their educational and cultural bias. This bias is especially pronounced in Aboriginal cultures where there may be a lack of formal schooling, and where different concepts of time, space and numbers may also be encountered.

Abas, Phillips, Richards, Carter & Levy (1996) discovered a highly specific discourse regarding dementia among their sample of Caribbean elders. Dementing individuals are understood to have the following features: “looks unkempt; comes out half-dressed; cries as though lost; believes they have eaten what they have not; and that they are penniless or that they still have to go to work” (1996, p. 1098). These discourses point to a culturally embedded mode of describing and understanding dementia symptomatology.

Within the South African context, Bodibe (1992) has explored the semantic relationship between African traditional names of diseases and medical terminology. According to his extensive lexicon reveals no equivalent terms in either Sotho or Zulu - two of the most widely spoken African languages - that even approximates the western biomedical model of dementia.

Ensink & Robertson (1997) explored discourses of illness among the Xhosa. Although not related to dementia, this research contributes to an understanding of the cross-cultural construction of illness among the South African Xhosa. It was found that a “multiplicity of illness beliefs” exist in this community and that “these were much more fluid than previously expected” (1997, p. 141). The most important finding of this study was that “patients and families combine concepts and explanatory notions from indigenous, biomedical, psychosocial and lay systems” (1997, p. 141) in constructing attributions regarding the causes of illness.

The preceding discussion shows that there is tremendous cultural variability in discourses and understandings regarding those conditions which Western medicine defines as dementia. These cultural understandings demonstrate that individuals from different cultures describe and explain cognitive impairment in language that has often little or no approximation in medical terminology. The work of diagnosing and treating dementia, as well as that of conducting cross-cultural epidemiological studies, must therefore take into account this complex interplay between culturally and linguistically bound understandings on one hand, and objectively observable brain pathology and clinically significant cognitive deficits on the other.

2.3 The Mini-Mental State Exam (MMSE)

Within western medicine, the formal assessment of dementia involves the use of various tests and screening instruments. The most widely used of these instruments is the Mini-Mental State Exam (MMSE), developed by Folstein, Folstein & McHugh (1975). The MMSE is the most commonly used cognitive screening measure for dementia, both internationally and locally. The MMSE is a 30-point standardized questionnaire that tests a restricted set of functions across cognitive domains known to be compromised in dementia. Administration is brief and scores below 24 are considered abnormal, indicating possible dementia.

The MMSE is used primarily as a screening instrument to identify cognitive impairment characteristic of dementia. It is also employed by epidemiological researchers to estimate rates of dementia in large populations, and for diagnostic purposes the MMSE is included as part of a battery of neuropsychological cognitive tests. Although diagnosis is never made on the basis of MMSE scores alone, the MMSE is widely considered by clinicians to be a reliable indicator of cognitive status.

The MMSE is attractive to clinicians and researchers alike because its widespread use facilitates comparisons between groups. With regard to the etic-emic distinction, the MMSE is clearly an etic instrument in that its use is informed by the assumption that it is measuring phenomena that exist universally regardless of the population under consideration. There are clearly shortcomings to this approach as there is substantial evidence that education levels and literacy contribute significantly to variations in MMSE test scores. The following literature regarding the use and application of the MMSE exemplifies the problems of employing a universalist methodology for cross-cultural purposes:

2.3.1 The MMSE: The problem of education

Accurate and appropriate assessment of dementia becomes problematic when applied to a multicultural society such as South Africa. This is because the most widely used screening devices sample the individual's current cognitive status as reflected on

Western-style test tasks, and these scores are compared against normative data typically derived from Western populations. The MMSE has been shown to be biased in favour of respondents with higher education and psychometric intelligence, and to lack validity when employed in non-Western contexts (O'Connor, Pollitt, Treasure & Reiss, 1989a; Jagger, Clarke, Anderson & Battock, 1992). In this regard, Hall *et al.* have noted that: "The ability to construct a cognitive evaluation consisting of items relative to orientation, memory and language which is not correlated with education, remains elusive" (1993, p. 13).

The reason for this is that the MMSE was developed in the context of the cognitive organization and ability of urban, literate populations of similar cultural backgrounds (Ardila, Rosselli & Rosas, 1989). However, when the MMSE is applied cross-culturally to populations with widely different levels of education and literacy, certain confounding variables become apparent. Crucially, the MMSE tests cognitive skills, representative of highly trained and learned tasks, that are developed through years of formal schooling. Thus, neuropsychological measures such as the MMSE can be said to be testing not universal cognitive abilities, but specific learned abilities acquired through the process of formal schooling.

Wilder, Cross, Chen, Gurland, Lantigua, Teresi *et al.* (1995) explored the diagnostic efficacy of 5 well-known brief cognitive screening instruments, including the MMSE, across various criteria. They found that when the clinical population consisted of

persons from groups with low levels of education, all scales produced large numbers of false positives. Having conceded the educationally biased nature of tests such as the MMSE, the authors stated that “it would be foolish to recommend they not be used because they are already so widely used and therefore permit many useful comparisons among studies and samples” (1995, p. 106). However, even within western populations there are limitations to its validity sufficient to raise some concerns. In non-western populations these methodological problems are more severe.

The literature abounds with studies that demonstrate problems in using the MMSE on particularly multicultural or community populations. Liu, Teng, Lin, Hsu, Guo, Chou *et al.* (1994) examined the relationship between the MMSE and demographic variables of age, education and gender among a community sample in Taiwan. They found that educational background affected performance on all but two items, thus making it impossible to differentiate between test bias and dementia.

This is of particular concern when assessing population groups with high levels of illiteracy and low levels of formal education. There is a serious risk when employing culturally biased tests that dementing individuals will be incorrectly identified as normal (false negatives) and thus not receive appropriate care. The challenge is thus to find a screening instrument that does not have cultural and educational bias, and that is able to screen for dementia in a manner consistent with the culture and language of the

population under study (Hall, Hendrie, Brittain, Norton, Rodgers, Prince *et al.*, 1993).

Shuttleworth-Jordan however, cautioned against developing a "nihilistic, or despairing attitude [which] promotes a view that all our existing tests should be abandoned and new culturally relevant and appropriately standardized tests should be designed" (1994, p. 3). These challenging comments, it should be noted, apply most to clinical settings in which relatively highly educated individuals from multi-cultural populations are encountered. It is in these settings that the author "strongly supports the use of readily available, standard psychological tests" (1994, p. 6). However, the use of currently available cognitive screening tests remains problematic when applied to cross-cultural population groups with low levels of education, English-language skills, and urbanization.

The MMSE also appears to be affected by *high* levels of education with the resultant bias presenting the risk of false negative diagnosis. Kawas, Segal, Stewart, Corrada & Thal (1994, p. 605) suggested that "individuals with dementia with higher education may compensate for loss of cognitive ability through collateral strategies" and thus these may score higher on cognitive tasks in the early stages of dementia, giving rise to misdiagnosis. Christensen, Korten, Jorm, Henderson, Jacomb & Rodgers (1997) used the MMSE in their investigation of the relationship between education and decline in

cognitive performance. They concluded that “education may compensate for neurodegenerative damage rather than protect against them” (1997, p. 323).

2.3.2 Further problems on the use of the MMSE

Apart from the confounding effects of education, the MMSE has been found to be problematic in other ways. The MMSE is only able to indicate cognitive impairment at the time of examination, and thus can provide no information of degree of change over time. Providing a static measure of an individuals cognitive ability is of limited clinical utility when one considers that dementia is characterized by progressive and insidious decline. As such “mild cases in particular are likely to be under-ascertained when classification is solely based on clinical examination and psychometric results” (Kawas *et al.*, 1994, p. 901).

Cross-cultural researchers have also noted that the MMSE tends to evaluate the individuals cognitive status using criteria far removed from the conditions of everyday life. Thus rural populations may never haven taken cognitive tests before and therefore lack generalizable test-taking skills to help optimize their performance. They may however have good cognitive skills that are useful in their every day lives, yet these are not reflected on their test performance (Liu *et al.*, 1994).

Applied in cross-cultural settings, MMSE scores may also be confounded by performance bias in individuals unfamiliar with the nature of the test situation. Zhang, Katzman, Salmon, Jin, Cai, Wang *et al.* (1990) found that illiterate individuals in Shanghai, China, showed less motivation and confidence than their literate counterparts. Inability to answer certain items tended to lead to a reluctance or refusal to answer further questions which they found difficult.

Similarly, O'Connor *et al.* (1989a) noted that substantial numbers of elderly in their sample found the MMSE threatening and therefore performance anxiety needed to be taken into consideration when interpreting their scores. Both the above studies support Anastasi's (1988) assertion that a testing situation may introduce bias when there is a cultural distance between the respondent and the examiner, a lack of familiarity of the respondent with the test-taking situation, and lower levels of motivation toward achieving maximal performance on the test.

In spite of growing concerns regarding the educational, literacy and cultural bias associated with the MMSE, the fact remains that the MMSE is the most widely used screening instrument for dementia worldwide. Copeland (1990) stated that before new cognitive techniques are introduced it should be demonstrated that they have substantial advantages over existing measures. The following section reviews the literature regarding Informant Questionnaires, highlighting the advantages and applications of this approach to dementia screening.

2.4 Informant Questionnaires

In response to methodological concerns regarding the MMSE, particular interest has recently been paid to the use of Informant Questionnaires (hereafter: InfQs), where a relative or caregiver of the individual provides information regarding behavioural changes, or cognitive decline, over time. InfQs attempt to access information relating to the individuals everyday life by asking a relative about changes relating to memory performance, orientation, language and praxis. InfQs thus cover the domains known to be compromised in dementia.

The advantages and features of Informant Questionnaires described in the following sections suggest that InfQs offer a promising alternative to the MMSE in screening for dementia. InfQs appear to be particularly useful in contexts involving poorly educated or multicultural populations.

2.4.1 Advantages of Informant Questionnaires over the MMSE

The most notable advantage of using Informant Questionnaires to screen for dementia is that neither education (Ritchie & Fuhrer, 1992), social class (O'Connor *et al.*, 1989b), nor literacy (Jorm, 1992) confound the data. Although InfQs scores correlate highly with MMSE scores, IQ scores have been shown to be independent of the pre-morbid factors that consistently confound MMSE scores.

Ritchie & Fuhrer (1992) compared 3 types of screening measures, using Receiver Operator Characteristics (ROC), to assess their relative discriminability. InfQs were found to be as efficacious as both the clinician's assessment and a cognitive battery, yet without being affected by education and premorbid ability. In addition, Tierney, Szalai, Snow & Fisher (1996) found that informants' perceptions were a better indicator of dementia than were the perceptions of the patients themselves.

Apart from being unaffected by education and premorbid ability, InfQs offer several other advantages over the MMSE:

- InfQs circumvent the problems associated with performance bias - inherent in cognitive screening measures such as the MMSE - by accessing information on the individual's activities of daily living. This makes InfQs particularly applicable for use with rural or illiterate populations.

- Whereas the MMSE samples cognitive impairment at the time of examination, InfQs provide information reflecting the degree of change over time and are thus particularly sensitive to milder forms of dementia. InfQs are also particularly useful in indicating cognitive decline rather than just current cognitive impairment, and thus are effective in identifying early signs of dementia.

- The use of InfQs leads to a greater acceptance rate from participants (Ritchie & Fuhrer, 1992). The use of the MMSE by contrast has resulted in high refusal rates among participants unfamiliar with or threatened by the interrogative nature of the testing process.

- A further advantage is that Informant Questionnaires typically provide high quality information in terms of phenomenological richness, as well as being a cost-efficient means of accessing this information (Kawas *et al.*, 1994).

- Informant Questionnaires have been shown to have a high correlation with cognitive screening tests in the assessment of dementia, while not being biased against premorbid ability, and are thus suitable for educationally disadvantaged participants (Jorm, 1994; Lenger, de Villiers & Louw, 1996; Morales, Bermejo, Romero, & Del-Ser, 1997). In addition, reliability has been shown to be high, both in terms of internal consistency and test-retest reliability (Jorm *et al.*, 1991; Ritchie & Fuhrer, 1992).

2.4.2 Significant Informant Questionnaires

This section will briefly discuss several important Informant Questionnaires, highlighting their merits and applications.

The **Cambridge Mental Disorders of the Elderly Examination (CAMDEX)** was developed by Roth, Tym, Mountjoy, Huppert, Henrie & Goddard (1986). The CAMDEX is a structured psychiatric interview schedule emphasizing the diagnosis of dementia in its early stages. The CAMDEX includes a mental status examination, formal cognitive testing, and an informant questionnaire containing items relating to memory and orientation. Results indicated that the informant questionnaire component correlated highly with the results of the mental status examination and was thus a reliable guide in indicating cognitive decline.

O'Connor, Pollitt, Brook & Reiss (1989b) used the CAMDEX with participants selected on the basis of a dementia positive score as reflected on the MMSE. Their sample included large numbers of poorly educated people who scored below the cut-off point on the MMSE, but showed no signs of dementia when assessed by the CAMDEX. This study is of value in demonstrating that informant histories contain the information needed to distinguish between patients who have never performed at a high level and those whose cognitive abilities have deteriorated.

The **Informant Interview** is a 26-item interview scale developed by Jorm & Korten (1988) to assess intelligence and memory changes by comparing the individual's present functioning with that of 10 years previously. The Informant Interview correlated highly with MMSE scores and was less affected by premorbid ability. The authors discovered though that the instrument was restricted by the limited availability of informants who had known the individual for 10 years. Research has also indicated that relatives may find it difficult to accurately remember the individuals performance 10 years previously (Jorm *et al.*, 1991).

Notwithstanding these limitations, Jorm, Scott, Cullen & McKinnon (1991) developed the **Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE)**, a self-administered version of the above instrument. The authors used the IQCODE in comparison with the MMSE in a sample of elderly patients. Their results showed that the IQCODE performed as well as the MMSE when compared against clinicians' diagnosis. Unlike the MMSE however, the IQCODE was found to have little correlation with premorbid ability, thus indicating its usefulness in assessing educationally disadvantaged individuals. This study also demonstrated that the IQCODE had better test-retest reliability than the MMSE.

Mulligan, Mackinnon, Jorm, Giannakopoulos & Michel (1996) found that although the IQCODE and the MMSE were equally efficacious in discriminating cases of dementia from non-cases, the IQCODE was unrelated to patient's educational attainment or

premorbid intelligence. They cautioned, however, by noting that data from the informant questionnaire may be influenced by non-cognitive factors such as the affective state of the individual and the informant, the personality of the individual, and the quality of the relationship between the individual and the informant.

A similar finding was reached by Jorm, Broe, Creasey, Sulway, Dent, Fairley *et al.* (1996) in their study of the validity of the IQCODE in screening for dementia. Their analysis showed that although as efficacious as the MMSE, the IQCODE was influenced by attributes of the informant. They concluded by writing that in terms of the relative merits of the MMSE and the IQCODE, "it is desirable to use both types of cognitive assessment" (1996, p. 138). In contrast a Canadian study concluded that "using both cognitive and informant data does not add much, if any, discriminating power to that provided by the informant score alone" (Hall *et al.*, 1993, p. 13). Morales, Bermejo, Romero & Del-Ser (1997) suggest that benefits tend to outweigh disadvantages, and that Informant Questionnaires in general are particularly useful in community-based studies where it has high validity in population-based samples; involves a short administration time; and can be easily administered by health care workers without any specialized training.

Kawas *et al.* (1994) designed a study examining the sensitivity and specificity of a semi-structured informant interview, the **Dementia Questionnaire (DQ)** in comparison with the criterion standard of clinical diagnosis. The study demonstrated

that all clinical cases of dementia were ascertained by the DQ (sensitivity 100%), suggesting that the DQ can be used alone to ascertain diagnosis with a viable degree of accuracy. The authors note that the study was limited in that the volunteer cohort had a relatively high economic status and educational level, and thus informants were able to provide considerable data in a sophisticated fashion. They caution that the high sensitivity of the DQ provided in this research may not generalize to individuals representing a broader range of racial, educational and cultural backgrounds.

2.4.3 The Détérioration Cognitive Observée (DECO)

The Détérioration Cognitive Observée (DECO) was developed by Ritchie & Fuhrer (1992) using retrospective interview data obtained from the relatives of 147 French-speaking elderly persons with diagnosed senile dementia. The DECO is a 19-item informant questionnaire with a 3-point Likert scale ranging from ‘better or about the same’ to ‘much worse’. The maximum score on the scale is 39 and the minimum is 0, with lower scores reflecting a greater decline in performance. The questionnaire provides information on behavioural changes over a one year period. Reflecting the diagnostic criteria for dementia, the DECO explores changes in memory for places, people, procedures and events, and also alterations in activity levels and the learning of new skills. The full DECO questionnaire is provided in the Appendices.

The DECO has a demonstrated high internal consistency and test-retest reliability, and furthermore was shown to be particularly effective in early case identification when compared with two widely used cognitive screening measures (Ritchie & Fuhrer, 1992). Analysis in terms of Receiver Operator Characteristics demonstrated its criterion validity. The DECO has a well established efficacy in screening for dementia as it has been validated within a case-control study using both DSM-III (R) and Clinical Rating Criteria.

The DECO has two significant advantages over the IQCODE. Firstly, unlike the IQCODE, which requires an informant able to comment on a 10-year period, the DECO draws observations over a 1-year period and therefore suitable informants are easier to find. The second advantage is that the DECO employs a 3-point Likert scale as opposed to the 5 point scale used on the IQCODE and is therefore less likely to cause confusion on the part of the informant.

2.5 Cross-cultural validation of informant questionnaires

Cross-cultural research suggests that although Informant Questionnaires, such as the DECO, are suitable for assessing illiterate or educationally challenged populations, there are concerns that their validity is affected by cultural and linguistic variables. In terms of the emic-etic distinction mentioned earlier, there appear to be two main responses to these concerns.

The first response to the challenges of cross-cultural validation is to adopt a radical emic approach whereby the notion of adapting an informant questionnaire for cross-cultural purposes is abandoned as untenable. Researchers such as these feel that conceptual equivalence is not possible to achieve even with a rigorous translation procedure. The emic perspective thus entails the creation of culture specific screening instruments. Inherent in the emic/relativist position is a difficulty in conducting comparative research between cultures - if it is not possible to devise instruments with equivalent categories or typologies, how can we make cross-cultural comparisons?

Kim & Berry (1993) believe that such research is possible by conducting emic studies in different cultures and then exploring the commonalities existing between those cultures. In this way, the authors reach what may be termed a 'derived etic' where any overarching categories emerge from local studies and not from assumptions imposed by the researchers.

This is then the second main response to the challenges of cross-cultural validation: the creation of instruments achieving a derived etic. The key advantage of the derived etic approach is that while cultural diversity is incorporated, it is not at the expense of the instrument's cross-cultural comparability.

2.5.1 Issues relating to cross-cultural translation

The manifold advantages of Informant Questionnaires have indicated to several researchers that this approach to dementia screening is suitable in cross-cultural contexts. Adapting an informant questionnaire for use in a cultural context different from its place of origin entails a rigorous process of validation. This process is influenced by the peculiarities of each situation and the instrument may require substantial modification in order to accommodate the cultural norms of a given population.

Hall *et al.* (1993) harmonized their Community Screening Instrument for Dementia (CSID) for use with both Cree-speaking native Indians and English speaking residents of Winnipeg, Canada. They employed a rigorous process of item selection, adaptation, translation, consensus translation, back translation, and revision. The authors used the translation process as preparatory work laying the foundation for subsequent small-scale pilot testing for acceptability, large scale pilot testing, further analysis and finally, determination of cut-off scores. Similarly, Prince (1997), in his discussion on dementia research in developing countries, concluded that even with meticulously developed instruments "[t]ranslation and back translation should be the beginning rather than the end of the validation procedure", and furthermore "the discriminating characteristics of the instrument must be re-calibrated in the new setting" (1997, p. 4). However as Canino, Lewis-Fernandez & Bravo cautioned: "The adequacy of a diagnostic

instrument in a given culture does not guarantee its reliability or validity in another, even given a faithful translation" (1997, p. 173-174).

The data from the Hall *et al* (1993) study showed that their resultant Community Screening Instrument for Dementia accorded with clinical diagnosis in 89% of the cases across both populations. The methodology employed in this study by Hall *et al* (1993) exemplifies a well-constructed derived etic where cultural and linguistic diversity is incorporated within a screening instrument that retains cross-cultural validity and reliability.

Exploring cultural, linguistic and contextual factors in validating a screening instrument for Aboriginal elders in Manitoba, Kaufert & Shapiro discovered that "one of the most significant methodological issues in cross-cultural validation of a screening instrument is that of assessing bias associated [with] language translation and the cultural appropriateness of functions evaluated" (1996, p. 277). In keeping with the approach advocated by Hall *et al.* (1993), the authors aimed to develop a modified assessment tool consistent with the culture and language of their research population. Their work entailed striving to achieve cross-cultural equivalence through "finding appropriate vocabulary and developing functional inventories which evoke comparable responses in other cultural contexts" (Kaufert & Shapiro, 1996, p. 278). The search for inventory equivalence in translated instruments is thus the central challenge in arriving at a derived etic. An emic perspective is required in coming to terms with culturally-

specific factors, and rigorous methods need to be employed in incorporating this factors within a cross-cultural screening tool.

It is clear then that although promising as a cross-cultural screening tool, an informant questionnaire intended for use in a heterogeneous cultural environment faces certain methodological challenges. Canino, Lewis-Fernandez & Bravo (1997) advocated "culturally informed mental health research…via a constant iterative process of cultural adaptation of research protocols" (1997, p. 164).

Concurring with Hall *et al.* (1993), the authors stated that:

> Unless the assessment tool used for diagnosis is developed in the culture for which it is intended, its use requires a comprehensive translation and adaptation process. The resulting instrument must be capable of identifying similar phenomena to those identified by the original version but in a dissimilar socio-cultural context" (Canino, Lewis-Fernandez & Bravo, 1997, p. 174).

The task of the cross-cultural researcher is thus to achieve a derived etic through adapting the instrument by integrating cultural information derived from anthropological approaches, thereby enabling the "[adjustment of] diagnostic algorithms to local phenomenological diversity" (Canino *et al.*, 1997). The work of Hall *et al* (1993) and Kaufert & Shapiro (1996) exemplifies this approach.

2.5.2 Integrating ethnographic information

The preceding discussion regarding translation shows that it is particularly important for a dementia screening instrument to incorporate attributions and discourses specific to the culture under consideration.

Rogler advocated enmeshing an "incessant, basic, and active preoccupation with the culture of the group being studied throughout the process of research" (1989, p.296). The value of such a radical emic is that "Ethnographic accounts could provide data that would contribute to the development of more sensitive instruments and thus facilitate case ascertainment in epidemiological surveys" (Smith, 1996, p. 268).

Angel and Thoits have demonstrated that "culture influences the probability that individuals notice specific deviations from physical or emotional well-being and the probability that these deviations will be labelled abnormal" (1987, p. 484). Given that information is provided by a proxy in the case of informant questionnaires, these comments are particularly germane.

These researchers support the relativist notion proposed by Smith (1996) in his critical review of cross-cultural research on Alzheimer's Disease. He wrote that since cultural modalities "pattern the expression of symptoms of cognitive decline in ways that may

not be assessed accurately by epidemiological instruments originally normed on Anglo-Saxon populations" cross-cultural screening "should therefore be preceded by extensive ethnographic accounts of how members of targeted cultures interpret disease, categorize symptoms and respond with culturally relevant treatments" (1997, p. 256). Such ethnographic ground work is the basis of the relativist approach to screening for dementia cross-culturally.

The assessment of dementia in a multi-cultural context is thus particularly challenging, with the need being to measure cognitive impairment in a non-threatening and linguistically acceptable way (Pollitt, 1997). It may be suggested that the use of Informant Questionnaires may circumvent some of these problems, provided that a derived etic can be achieved whereby informants' idiomatic style of identifying, understanding and attributing mental illness could be included into the selected informant questionnaire. The semi-structured interview that follows the administration of the DECO in the Langa study, described in section 2.6.1 below, explored this possibility by gathering additional information regarding people's perceptions of memory loss and the consequences of aging.

2.6 Dementia research in South Africa

In response to the absence of dementia prevalence estimates for the South African population Lenger, de Villiers & Louw (1996) and, currently, de Villiers, Bryer & Louw (1998) have initiated research in this area.

2.6.1 The Langa study

Lenger, de Villiers & Louw (1996) conducted a pilot study investigating the efficacy of the DECO in detecting cognitive decline in the elderly. The researchers compared the DECO with both clinicians' diagnosis and MMSE scores, using a convenience sample of 20 elderly patients and their relatives attending a South African hospital. Results showed that the DECO correlated highly with the MMSE, indicating that the informant questionnaire appeared to be a suitable alternative to cognitive testing, and additionally offered the possibility of being developed into an effective cross-cultural screening device for use with individuals with widely differing levels of literacy and education.

The researchers noted, though, modifications were needed in order to incorporate certain cultural factors that emerged. Lenger, in a preliminary study, recommended that it is "essential that the items on the DECO be adjusted…in order to maximize its effectiveness" (1994, p. 22). Lenger, de Villiers & Louw (1996) similarly noted that

responses to certain questions suggested that modifications were required before the DECO could be used to diagnose dementia cross-culturally within South Africa. For these reasons, the researchers administered a semi-structured interview after the presentation of the DECO in order to provide data for substitute questions should certain DECO items prove non-discriminating in a local context.

2.6.2 The dementia case-ascertainment study

De Villiers, Breyer & Louw (1998) conducted a pilot study on 74 elderly, Xhosa-speaking people and their relatives in Langa, a black community outside Cape Town. The study is employing the DECO, a semi-structured follow-up interview, and concurrent clinical assessment, for dementia case ascertainment within this community.

A preliminary report noted that the agreement rate between clinicians' diagnoses and the diagnosis made by the DECO was lower than expected (de Villiers, Bryer & Louw, 1998). Agreement between clinicians' and relatives perceptions of normal and probable dementia cases was 69.4%. Reflecting on this discrepancy, the researchers considered the qualitative data provided by the semi-structured questionnaire.

The questionnaire was devised to explore informants attitudes and understandings of old age and cognitive disturbances. Included in this protocol was a clinical vignette (see Appendix) followed by focused questions. The vignette portrayed an elderly lady

lost and confused, and people were asked to describe their understanding of the situation. The questionnaire pursued notions of what constitutes normal and abnormal aging, expectations of elderly people, and attributions around illness and memory deficits. With the exception of a psychosocial profile of Coloured elderly conducted by Elk, Swartz & Gillis (1983), no such inquiry has been conducted in South Africa before.

Drawing on information provided by relatives in the semi-structured interview, the researchers hypothesized that information derived from the informant questionnaire may be influenced by what is considered normal or abnormal within the cultural framework of the informants (De Villiers, personal communication). In addition, de Villiers has noted that little is known regarding lay concepts of dementia in developing countries and we should "therefore continue to ask questions about people's beliefs and modify our questions accordingly" (De Villiers, personal communication).

Moreover, the follow-up interview has provided interesting data regarding people's 'idioms of distress', that is, the language and concepts employed to convey phenomenological understandings and definitions of ill-health specific to this population. It has become apparent that it is necessary to incorporate these idiomatic definitions and understandings within the DECO.

2.6.3 Outstanding problems

The original Langa pilot study (Lenger, de Villiers & Louw, 1996) and the ongoing case-ascertainment research (de Villiers, Bryer & Louw, 1998) have provided encouraging results that suggest the viability of using the DECO as a screening instrument for the multi-cultural South African population. Several outstanding problems remain, however:

- Culturally based perceptions regarding the elderly appear to have a confounding influence on DECO scores. The nature of these informant perceptions requires elaboration.

- The issue of whether these perceptions are specific to the Xhosa-speaking Langa community or in fact are more widely based, remains uninvestigated.

- Although it has been recognized that certain DECO items require modification, no empirically sound approach has been developed toward this end. Moreover, it is unclear whether such modifications will compromise the validity of the DECO for use across groups.

CHAPTER 3: METHODOLOGY

The methodology is presented in the following order:

3.1 Aims and Objectives

3.2 Respondents

3.2.1 Bothasig

3.2.2 Langa

3.3 Research instruments

3.3.1 Demographic questions

3.3.2 Details of the interview protocol

3.3.3 The clinical vignette

3.3.4 Clarification session with key informant

3.4 Procedure

3.4.1 Bothasig

3.4.2 Langa

3.5 Coding

3.6 Analysis

3.6.1 Quantitative analysis

3.6.2 Synoptic discourse analysis

3.7 Cross-cultural Considerations

3.1 Aims and Objectives:

In keeping with the rationale for this study outlined in the Introduction, the aims and objectives of this research are the following:

- To identify and compare perceptions and understandings regarding cognitive deficits within the Bothasig and Langa communities.

- To identify language and concepts which the informants use to describe and explain dementia related cognitive decline.

- To determine what attitudes the Bothasig informants have towards the elderly with regard to cognitive deficits and then to compare these data with those attitudes drawn from the Langa study.

- To assess whether or not informant perceptions may confound observational data provided through the DECO questionnaire.

- To provide, on the basis of this analysis, empirically sound recommendations for the modification of certain key DECO items as a screening instrument for the diagnosis of dementia.

3.2 Respondents:

A total of 146 respondents were used in this study, 71 of which were drawn from the Langa study conducted by de Villiers, Bryer & Louw (1998), and 75 from the Bothasig sample. For each community the sampling procedure is outlined and a generalized description of the two communities is provided.

3.2.1 Bothasig

Bothasig is a suburb located approximately 20 km outside Cape Town city center. The total population is 11 000. The community is well serviced by 2 schools, a library, a large shopping mall, and readily accessible police and medical services. 3-4 bedroom houses are typically occupied by a small family with an elderly relative in residence. Crime in Bothasig is well-controlled and police patrols are regular and conspicuous.

On the basis of the demographic data obtained from the Langa sample, a suitable comparison group was sought that represented an English-speaking population having similar socio-economic and demographic levels to that of the Xhosa-speaking Langa group. The Bothasig group was selected on the basis of demographic information drawn from the 1991 National Census as figures from the 1996 census were not yet available. According to these figures, the Langa and Bothasig informants represented lower-middle class communities with similar levels of education. Both groups had a

high proportion of elderly people, and represented accessible communities within the greater Cape Town area. Respondents within Bothasig were selected through randomized cluster sampling.

3.2.2 Langa

Langa is a well-established Xhosa-speaking community located approximately 15 km outside the Cape Town city center. The total population of Langa is 34 000. The community consists of both municipal houses and a growing number of informal dwellings. A recent trend is that owners of municipal housing are leasing areas of their property for informal dwellings. Such dwellings, as well as the proliferation of shacks on the outskirts of Langa, are catering for the influx of migrants from the former Transkei, who come to Cape Town in search of work. The demographics of Langa are thus constantly changing, and the reliability of census figures is questionable since many residents are not officially there! Resources are inadequate with only 2 schools, one police station, and an understaffed primary health care facility. Crime is problematic and unemployment is high.

The Xhosa-speaking Langa population was randomly selected through cluster sampling to obtain a representative sample based on population figures. This work was done by Cora de Villiers, who initiated the Langa pilot study (Lenger *et al.*, 1996), with the assistance of translator. The data from the Langa semi-structured interviews

has not been published and permission to use this data was provided by Cora de Villiers.

3.3 Research Instruments:

A semi-structured questionnaire was employed identical to that used in the original Langa follow-up questionnaire devised by Cora de Villiers. The research questionnaire was designed to yield as much information as possible about the informants' attitudes, beliefs and understandings regarding cognitive changes in old-age. The informants were instructed to answer in terms of their experience of an elderly relative with whom they were familiar. This condition was important as certain questions ask the informant to reflect on changes over time. The full questionnaire was piloted on 10 randomly selected Bothasig residents. On the basis of this trial, the questionnaire was modified to exclude 3 questions that provided redundant information. The final questionnaire consisted of 3 parts:

3.3.1 Demographic data

Information was gathered regarding the informants' age, gender, highest educational levels and familial relationship to the elderly person. Information regarding the elderly persons age, gender and highest educational level was also gathered.

3.3.2 Questions regarding perceptions of cognitive decline

The second part of the questionnaire focused on questions around informants' beliefs and expectations regarding the elderly, with particular emphasis on their attitudes to forgetfulness and cognitive decline in old age. Key questions that made up the interview questionnaire, and the rationale for each, are elaborated on below. Note that only those questions elaborated on in the Discussion are presented here. The full questionnaire is provided in Appendices.

Question 1 asks "Is your elderly relative forgetful?", and if so, "What does he/she forget?". This question was chosen to see whether the existing questions relating to forgetfulness on the DECO were relevant to South Africa. Thus the frequencies of responses from this question may be compared between the Langa and Bothasig groups to determine whether the objects of forgetfulness are similar.

Question's 2, 3, 4 and **5** explore informants' attributions regarding forgetfulness in the elderly. Question 2 asks the informant to consider reasons for their relatives forgetfulness ("Why do you think _____ is forgetful?), while question's 3 and 4 ask more generally how common memory decline is among the elderly (3. Do you think all old people are forgetful, or only some of them? 4. Why do you think that it is so?). Question 5 asks whether or not forgetfulness is an illness (5. Do you think

forgetfulness in old age is an illness?), with the informant then asked to explain his/her answer.

Questions 2 to 5 were chosen specifically to access peoples notions of what is considered "normal" for the elderly, and in particular whether or not forgetfulness is a common and benign consequence of growing old, or whether it constitutes a symptom of an illness. The issue of causal attributions on the part of informants is important since there are indications that responses to informant questionnaires are influenced by what is considered normal or abnormal (Rajkumar, Kumar & Thara, 1997; Pollitt, 1997; de Villiers, personal communication).

Question 9 asks: "Should a person's financial independence be limited by their age?" Responses to this question provides insight into the expectations and perceived abilities of the elderly. The question also aims to explore the discriminability of Item 8 of the DECO by discovering whether the informants perceive their elderly relatives to be financially independent.

Question 10 asks: "What duties or responsibilities do you think an elderly person should have in the family?" By asking the informant to comment on the duties or responsibilities that are expected of the elderly relative the question accesses expectations of the elderly and the role of the elderly relative within the wider family.

This is of great relevance when constructing an informant questionnaire as peoples expectations of the elderly are likely to influence their observations.

3.3.3 The clinical vignette

The third part of the interview protocol provided a clinical vignette depicting an elderly lady exhibiting florid signs of cognitive disturbance. Subsequent questions explore informants understanding of this situation and their interpretation of the character's behaviour. The vignette was presented to all the Bothasig respondents and a subgroup of Langa respondents (n=27).

Part B of the questionnaire protocol presents the informant with a clinical vignette followed by 4 questions (see Appendix):

> It is early in the morning. About 5 'o' clock. On your way to work you meet an elderly lady dressed only in underwear. You start wondering about this situation. At last you decide to have a closer look and help. It is then that you realize that this elderly lady does not know where she is. She is very confused. The only thing she can remember is that she is from Pinelands.

Participants were asked *inter alia* what they thought was happening to her, and what they thought others would think or do. The vignette was designed to elicit further

information regarding the informants understandings of what constitutes abnormality in the elderly. The vignette is purposefully ambiguous in order to give the informants the opportunity to respond creatively. In doing so, informants are likely to employ idiomatic language that is drawn from their cultural background. It is these idiomatic understandings that need to be incorporated into an informant questionnaire for it to have cross-cultural applicability.

3.3.4 Clarification interview with key informant

The Langa data, gathered by Cora de Villiers with the assistance of a Xhosa speaking translator, was translated into English as the data was gathered. During the processing of the data, it became apparent that certain terms were used ambiguously. In order to obtain clarification, an informant was selected with specific knowledge regarding the Xhosa-speaking Langa community, and an interview was conducted. Areas of ambiguity and concern were listed which then served as the basis for an interview guide. This guide was used as the basis for the discussion with informant.

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For this reason an informant was sought that would be able to clarify and explain certain terms and phrases used by Langa informants. An 37-year old employee in the Rhodes University Department of Psychology was chosen as a key informant as he was Xhosa-speaking, familiar with the Langa context, and had an excellent command of English. An hour-long interview was conducted in which the informant was asked to

discuss a range terms and attributions used by Langa participants. During the interview notes were made regarding the informants comments, suggestions and interpretations.

3.4 Procedure:

3.4.1 Bothasig

On the basis of the cluster sample drawn from a Bothasig area map, 75 households were identified. Each of these households were visited over a one month period by either the current researcher or a research assistant. The assistant was a middle-aged English speaking lady resident in the Bothasig community. She was trained in administering the questionnaire through role playing with the current researcher. After the research assistant had gathered 5 interview protocols, a telephonic feedback session confirmed that the data gathering was proceeding smoothly.

In certain instances, members of a particular household were not available despite repeated visits and therefore the next household along the street was selected. On each occasion the questionnaire was administered face-to-face with a relative of an elderly person. In order to qualify, the relative needed to be very familiar with the elderly person, and in regular contact. For the purposes of this research, an elderly person was defined as someone over the age of 65.

3.4.2 Langa

The semi-structured interview was administered to 71 respondents selected on the basis of a randomized cluster sample. The interviews were conducted by Cora de Villiers, and a Xhosa-speaking female research assistant, employed at Groote Schuur as a translator. The data were gathered in 2 phases. In the first phase of data collection, 44 interviews were conducted using the semi-structured interview protocol. After this data was processed, the researchers decided to add a clinical vignette to the interview protocol. Thus in the second phase of data collection the semi-structured interview and the clinical vignette were administered to a further 27 respondents.

3.5 Coding

The process of coding was done independently by the present researcher, and Cora de Villiers, the author of the original Langa study. The coding was conducted according to the following process:

- The informant responses across both groups were categorized for each question into naturally occurring response groups through identifying typologies emerging from the data (Taylor & Bogdan, 1984).

- The present researcher and Cora de Villiers then compared classification schemes and discussed discrepancies.

- Responses were recoded until agreement on the coding for each unit of data was reached.

Since respondents were encouraged to answer freely in their own words, the responses were coded according to conceptual rather than semantic typologies. This was done to circumvent the confounding effect of culturally based language differences. Thus for example the Langa response “worries about grandchildren” as a reason for memory decline was considered to be phenomenologically similar to the Bothasig response “she’s anxious about her family”. Both these responses were coded as “Worries”.

A further decision had to be made regarding multiple responses to individual questions. With certain questions respondents provided several answers and it was therefore not possible to code these responses according to only one typology. In these instances one of two decisions were made. Where the response was dominated by a primary theme followed by peripheral suggestions, the primary theme was coded to the exclusion of the other responses. For example, a response such as “It is *definitely* Alzheimer’s disease, but it maybe its diabetes or worries” was coded as ‘Alzheimer’s’. In other cases, where the response contained plural themes emphasized equally, for example “It could be senility or just old age or possibly she’s mad” each response was

individually coded. For this reason tabulated response frequencies are reflected as percentages as certain respondents provided more than one answer.

3.6 Data Analysis:

The data was analyzed using two complementary approaches:

3.6.1 Quantitative analysis

The quantitative data was analyzed according to response frequencies, reflected as tabulated percentages. Where appropriate, specific hypotheses were analyzed with chi-squared tests and cross-tabulations.

3.6.2 Synoptic discourse analysis

In conjunction with a statistical treatment, the data was subjected to a synoptic discourse analysis in order to reflect the phenomenological dimensions of the informant's responses. The synoptic discourse analysis was conducted according to the following procedure:

- The data was re-read exhaustively after which thematic questions emerged. An example of such a thematic question is “What do Langa informants expect of the elderly within their community?”.

- The data was then reviewed for relevant responses and conceptual understandings, and then organized into a coherent form.

- Where ambiguities were evident, clarifying data provided by the key informant was incorporated.

- Finally, a synoptic summary of discourses around the thematic questions was created.

3.7 Cross-cultural considerations:

The Literature Review has discussed some of the methodological issues inherent in conducting cross-cultural research. Particular emphasis was paid to the relative merits of the emic-etic approaches. There is often a tension between these approaches that must be creatively managed by the cross-cultural researcher. The research questions in this study, for example, require a comparative analysis across the Langa and Bothasig groups, while at the same time respecting the cultural specificity of the data arising out of those respondents. For this reason, two forms of data analysis were employed; as

such this research endeavors to achieve a “derived etic” (Kim & Berry, 1993) whereby the integrity of the Langa data is not sacrificed at the expense of universally imposed response categories. Thus although the data is presented in tabulated form reflecting the frequencies of responses, the discussion considers the phenomenology of key responses as primary. These responses are presented verbatim in order to reflect the richness of these data.

CHAPTER 4: RESULTS

The Results are divided into 7 sections:

4.1 Informant demographics
4.2 Expectations of the elderly
4.3 Perceptions of memory impairment
4.4 Perceptions on cognitive disturbance: The clinical vignette
4.5 Information provided by the key informant
4.6 Synoptic account of Bothasig conceptualizations of and attributions about cognitive decline
4.7 Synoptic account of Langa conceptualizations of and attributions about cognitive decline

The Results employ two complementary modes of presenting the data arising out of this study. The tabulated percentages of response frequencies allow an immediate comparison that reveals key differences between and within groups. The verbatim accounts and synoptic summary present that data in a more discursive and descriptive manner.

Where relevant, the methodological concerns and coding issues are explained for certain questions.

4.1 RESPONDENT DEMOGRAPHICS

The following table indicates the group means for the informants in terms of age, years of education and literacy:

Table 1: Informant demographics

	LANGA	BOTHASIG
Age (years)	44.64	38.25
Education (years of education)	8.54	11.45
Literacy (percent literate)	95%	99%
No. of respondents	71	75

The relatively wide disparity between educational levels indicates that the demographic data drawn from the 1991 National Census was misleading. Either the demographic data was incorrect, or the composition of these two communities has changed since the time the Census figures were compiled.

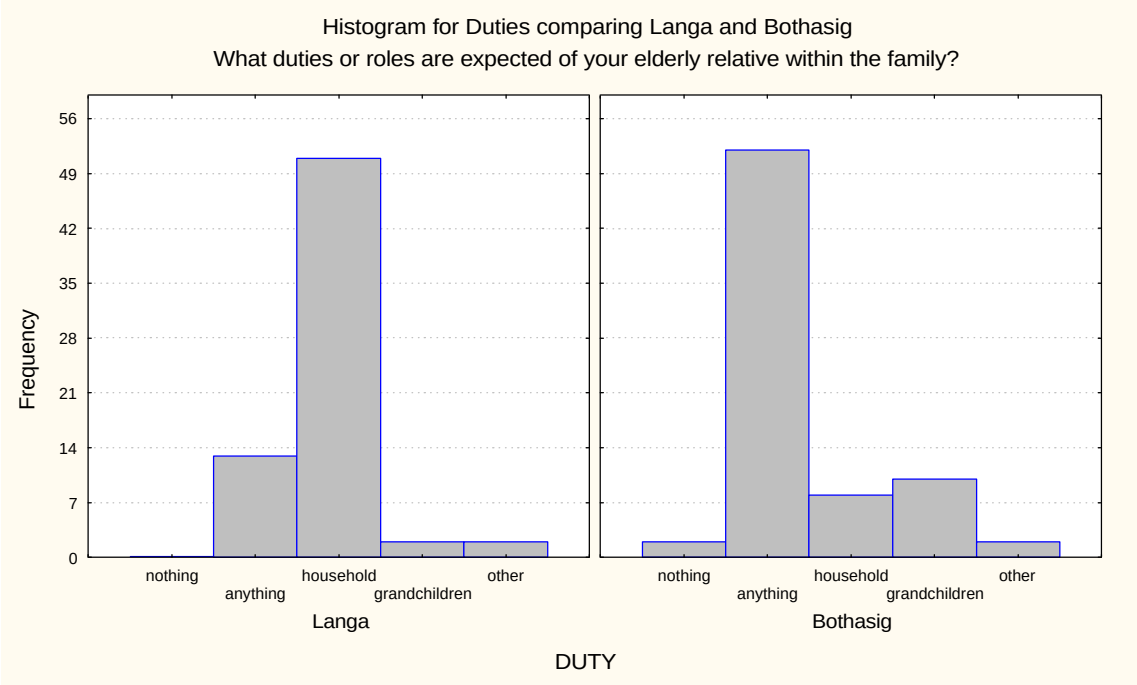
4.2 EXPECTATIONS OF THE ELDERLY

This section presents the results pertaining to 2 questions examining expectations of the elderly.

4.2.1 Duties in support of the family

Question 10 of the semi-structured questionnaire asks: “What duties or roles are expected of your elderly relative?”

The histogram below (*Illustration A)* depicts the different frequencies of responses between the Langa and Bothasig groups:



70% of the Bothasig group (*n*=52) feel that their elderly relative should be able to do "anything" they like within the home. Qualitatively, most respondents felt that their relative should do "anything they feel capable of doing". In contrast, 75% of the Langa group (*n*=51) expect their elderly relative to support the family with household tasks and duties. Qualitatively these household tasks were described as washing, cooking, and cleaning. These between-group differences are significant at *p*=0,01 (chi squared)

The majority of the Bothasig responses were coded according to the typology "Anything". Notably, respondents were frequently unwilling to elaborate, and attempts to probe generated only paraphrasing of the original answer. Typical responses included statements such as:

> Whatever she feels like doing
>
> Give them what they want to do
>
> What they like doing

They should do nothing

As little as possible

The majority of Langa respondents (75% / *n*=53) provided responses that were coded, by virtue of their phenomenological similarity, as “Household”. Typical of these are the following verbatim responses:

Those who can do washing, cooking and cleaning

Grandma must just go to church and sweep, that's why we get old before our time

Washing dishes and other light duties are enough

Something small, like mending broken things

Picking up rubbish in the yard

Washing dishes and her underwear and making her bed

She must keep herself busy in the house

Knitting bags from Checkers bags

The majority of the Langa group who detailed household tasks described one of 5 activities that they expected of their relative: washing (dishes/clothes); gardening; cleaning (sweeping/dusting); safe or small things; knitting or sewing; and tidying up.

4.2.2 Expectations around money

Question 9 asks "Should a person's financial independence be limited by their age?" Respondents were asked to elaborate on their answers. The results are presented in the table below:

Table 2: Response to question 9: "Should a person's financial independence be limited by their age?"

	Bothasig %	Langa %
Yes	20	57
No	80	34
don't know		9
total (*n*=)	*75*	*71*

The question of financial independence revealed notable differences between groups. Within the Bothasig group 80% (n=60) said that they would not attempt to restrict their elderly relative's financial independence, and that they would allow their relative to control their money until they died. By contrast, 57% (n=40) of the Langa respondents said that they **would** limit their relatives' financial independence.

The Bothasig respondents seem to equate personal autonomy with financial self-determination:

> They should manage money till they die; its important that they maintain control
> It is theirs to do with as they want; each individual should decide for themselves
> Up to the point where they are physically unable to do so
> There should be no limit
> As long as they feel capable; its their decision
> You can't impose a time limit on that sort of thing

Typical responses from the Langa group regarding the issue of financial independence indicate that respondents perceive financial management to be the province of the children or grandchildren of the elderly person:

> The children should help
> The grandchildren often take over
> She often puts her money where it becomes lost, so we must help
> It is dangerous for them alone
> Old people will forget to look after money

4.3 PERCEPTIONS OF MEMORY IMPAIRMENT IN THE ELDERLY

4.3.1 Introduction

This section will present respondent's perceptions regarding forgetfulness in the elderly. These data are meaningful given that the existing DECO is heavily loaded with questions around forgetfulness, appropriately accessing information regarding memory deterioration, which is a primary diagnostic indicator for dementia.

4.3.2 Does your elderly relative forget?

Respondents were asked whether their elderly relative was forgetful of not:

Table 3: Responses to question 1: "Is your elderly relative forgetful?"

	Bothasig (%)	**Langa (%)**
YES	52	65
NO	48	35
Respondents	*n= 75*	*n= 71*

Those respondents that answered "yes" to question 1 were asked to consider reasons for their relative's perceived forgetfulness:

4.3.3 Attributions for forgetfulness

In response to question 2 of the semi-structured interview "Why do you think your relative is forgetful?" the following answers were provided:

Table 4: Responses to question 2: "Why do you think your relative is forgetful?"

	Bothasig (%)	Langa (%)
old age	64	52
emotional	7	
worries		10
health	18	16
other	5	8
don't know	5	14
Responses (n=)	*n = 39*	*n = 50*

The table summary is reflected in percentages and certain respondents gave more than one answer. The coding categories are explained as the results are presented.

Of the total sample (*n*=146), 39 Bothasig and 46 Langa respondents reported that their elderly relative is forgetful. Of these respondents, 64% of the Bothasig group and 52% of the Langa group attribute their relatives memory loss to *old age*.

The majority of Bothasig responses constituted variations on the theme of memory decline as a benign and inevitable process associated with growing old. The following responses were coded as "old age":

> Its probably natural, she's just getting old
> Its just his age, its quite normal to be forgetful
> She's getting on a bit
> Just old age

Langa respondents employed very similar attributions, also coded as "old age":

> Its the age
> She's getting older

Because of her old age

Other attributions were provided. 18% of Bothasig and 16% of Langa responses were coded as “health”. This typology covers all physical health reasons used to account of the respondent’s memory problems. Langa responses included the following:

She is forgetful since she got sick - I’m not sure what sickness she has
She has been drinking for a long time, and now has memory problems for the last 2 years
She is forgetful because of the abuse of alcohol

Bothasig “health” attributions included various notions:

It’s just calcification of the veins
She has a heart complaint - I think the illness has caused the memory loss
The brain slows down, like the body

The coding typology “emotional” (7% Bothasig) covers reasons such as loneliness and boredom:

She is lonely now, and probably bored
She seems distracted and lonely

10% of Langa responses were coded according to the concept “worries”:

She has too many worries
She is old, and she worries about the children - one is in a wheelchair (coded as “old age” and “emotional”)
He has blood pressure and diabetes; he is also worried because he can’t give his wife sex (coded as “health” and “worries”)

Too many worries - son is behind bars, husband died and she couldn't bury him

"Other" attributions (5% Bothasig and 8% Langa) were coded when the meaning of the response was not clear:

When we talk, she will just keep quiet because she doesn't know what to say

Because of the concentration in the church

She's very busy; always doing things

Overall, responses to the question "Why is your elderly relative forgetful?" generated a variety of reasons, with old age being the most common attribution for memory loss across both groups.

4.3.4 Is forgetfulness considered typical among the elderly?

Informants were asked to consider whether memory loss was typical among the elderly in general, and to provide a reason for their answer.

Table 5: Responses to question 3: "Are most old people forgetful or only some of them?"

	BOTHA (%)	LANGA (%)
some	62%	59%
most	38%	41%
n=	*69*	*75*

The majority of respondents across both groups believe forgetfulness is not typical among the elderly and that only *some* elderly people have memory difficulties.

Respondents attribute forgetfulness in some old people to a diverse range of factors, summarized in Table 6:

*Table 6: Responses to question 4a: "Why do you think only **some** elderly people forgetful and not others?"*

	Bothasig (%)	Langa (%)
old age	22	9
health	32	26
worries	2	25
lonely/bored	31	
other	6	21
don't know	7	19
Responses (n=)	*n = 48*	*n = 43*

Those respondents that believe that forgetfulness is not typical among the elderly, attribute memory loss to a range of factors.

22% of Bothasig respondents identify old age as the reason why only some elderly people forget:

> You get old and start becoming forgetful
> Some people just get old and forgetful

9% of Langa responses were also coded according to the category "old age":

> Only a few forget - its the old age
> Very few forget - depends on the aging

These responses, typical of this coding category, appear contradictory. These respondents have stated that not all elderly people forget, and yet their reasons suggest that old age implies forgetfulness.

32% of the Bothasig group see health issues as contributing to memory loss:

> Only some forget - it might be old timers disease
> It really depends on health

This reference to "old timer's disease" was clarified by another Bothasig informant to mean "senile". Throughout the results, references to "old timer's disease" are distinguished from "Alzheimer's Disease" in spite of the phonetic similarity. In total, 4 Bothasig informants used this term.

26% of Langa respondents similarly gave physical health issues to account for the perception that only some elderly people are forgetful. The following Langa responses were coded as "health":

> Not all of them are forgetful, on depends on their health
> People who are not sick are not forgetful
> Some people drink
> With some people it is an illness; something lacking
> Only ill people are forgetful and not all old people are forgetful

25% of Langa responses centered around issues commonly involving the family. These responses were coded as "worries":

> Some homes differ where children neglect their elderly people, and old people are not physically fit to call them to order
> Problems with the family, and worries about the children

The young people are causing problems
Some people have worries

Only 1 Bothasig response (2%) was coded as “worries”:

Its the stress from their domestic situation

31% of Bothasig responses employed the following attributions, coded as “lonely/bored”:

They have no interests, they are only remember the past
There is no stimulation, only frustration and boredom
They have no interests and hobbies; they are not intellectually active
Their minds aren’t stimulated - just get put in old age homes and forgotten

Within the Langa group, a significant proportion (21%) provided a range of diverse responses (coded as “other”). This high proportion of “other” responses may indicate that the question was not fully understood by the respondent. Examples, in the respondents own words, include the following:

Only some are forgetful because they tell stories from long ago
It is their nature; it is the way they have been made
Some people are forgetful because we treat them like children

Of those informants who believe that *most* elderly people are forgetful (refer back to Table 2), 38% Bothasig and 40% Langa, the following reasons are provided. It is interesting to note that the range of attributions is significantly restricted when compared with those provided by respondents believing that memory loss is not typical among elderly people:

*Table 7: Responses to question 4b: "Why are **most** elderly people forgetful?"*

	Bothasig (%)	Langa (%)
old age	69	76
health	19	6
other	7	7
don't know	5	11
Responses (n=)	n = 52	n = 46

The majority of both groups believe that all or most elderly people are forgetful because of their old age. These Bothasig respondents (69%) see memory loss as typical among elderly people and they perceive a cause and effect relationship between old age and subsequent memory loss. These responses were coded as "old age":

> Old age makes them forgetful
> Its just old age - it happens to everyone I think
> When you get old everything deteriorates, including the memory
> Old age is just a process, you slow down
> Old age - we just wear out like machines

The majority of Langa respondents (76%) who see memory decline as typical similarly see old age as the reason. These responses were coded "old age":

> Most forget - its just their age
> Everyone that age does not have a good memory
> All old people become forgetful
> Most of them do forget - its the old age
> All of them forget at this age - they become like children
> When old people reach a certain age they forget

Among Bothasig respondents, 19% provided a range of health related reasons to account for their opinion that most elderly people are forgetful. The following responses were coded as “health”:

> They are not as fit as before and everything slows down
> Their brain cells are declining
> The brain gets tired like everything else
> Everyone slows down from 40. Some slow down quicker than others
> The brain gets worn out

6% of Langa responses were similarly coded as “health”:

> In the 60s it all changes; their energy changes and goes down
> It is the age and the health (coded as “health” and “old age”)

4.3.5 Memory decline as disease

Respondents were asked whether memory impairments constituted a disease process or not:

Table 8: Responses to question 5: “Do you think forgetfulness in old-age an illness?”

	Bothasig (%)	Langa (%)
No	44	64
Yes	53	27
don't know	3	9
Total	*n = 75*	*n = 69*

The table shows a difference between the Bothasig and Langa group, significant by chi -squared test at the, 02 level. The majority of Langa respondents (64%) believe that

forgetfulness in old-age does not indicate an illness whereas 53% of the Bothasig respondents do.

In considering these data it must be considered whether the term “illness” used in the question is conceptually equivalent across both groups. It is also worth considering whether any response sets are evident. Are respondents more or less likely to perceive forgetfulness as a disease if they have a relative who is forgetful? In total 85 respondents reported that their elderly relative was forgetful, 39 from Bothasig and 46 from Langa (see Table 2). Cross-tabulating these data from that arising out Table 3 above demonstrates no statistically significant relationship between viewing forgetfulness as a disease and whether the respondents relative was reported as forgetful.

Following up this question, reasons were provided for the respective responses. In Table 9 below, the highest response categories are provided across each group for the respective “yes” and “no” answers in response to question 5 (“Do you feel that forgetfulness in old age is an illness?”):

Table 9: Reasons for stating whether or not memory loss is a disease

	Bothasig		**Langa**	
Yes it is a disease	Alzheimer’s - 66% Health - 12% Don’t know - 7% Loneliness - 7%	53%	Health - 45% Worries - 20% Don't know - 8% Old age - 5%	27%
No it is not	Old age - 65% Loneliness - 18% Health - 8%	44%	Old age - 73% Worries - 14% Not sure - 7%	64%

Of the 53% of the Bothasig group who consider forgetfulness to be evidence of an illness, 62% specified Alzheimer's disease. The Langa respondents, the majority of whom do *not* attribute an illness (64%), believe forgetfulness is symptomatic of old age (73%). Old age is also the predominant attribution for the 27% of Bothasig informants who believe forgetfulness does not indicate a disease.

Bothasig respondents frequently employed precise and realistic attributions for viewing memory decline as a disease process. These responses, coded as "Alzheimer's / senility", constitute 62% of those who stated "yes memory loss is a disease". The following verbatim accounts suggest that these informants are attuned to a medical pathology underlying memory decline:

> Possibly stress or fatigue, maybe Parkinson's, Alzheimer's
> Alzheimer's or diabetes
> Senile dementia
> Something serious like Alzheimer's
> Mental disorder such as senility

Others attributed memory loss to less precise agents while viewing the phenomenon from a medical perspective. These responses were coded as "health":

> It is caused by calcification of the brain
> It is a lack of vitamins
> Pneumonia is common among the old and this can lead to senility
> Old timers disease

Overall, 42% (*n*=32) of Bothasig respondents used the terms senile, dementia or Alzheimer's in their responses. These terms were not cued by the interviewer. By contrast, none of the Langa respondents used these terms.

Among those Langa participants who consider forgetfulness as evidence of a disease process (27%), 45% of attributions center around physical health, as evidenced by the following responses, coded as “health”:

> It is a disease which goes in the body system and then it affects them
> It is a disease because diabetic people tend to forget
> After some illness
> Some kind of illness in the mind
> An illness, I am not sure what kind

The responses above indicate that these Langa informants employ medical attributions. Although no reference was made to “senility” or “Alzheimer’s” as was the case in Bothasig, certain Langa responses do indicate a conceptual understanding of dementia. These responses were coded as “health”:

> Their minds get looser and they become like children
> It comes from stick fights which can affect you in old age
> Some kind of illness in the mind, like a mental illness

Certain other disease attributions were highly specific. These are also coded under “health”:

> An illness caused by sugar diabetes, high blood pressure or possibly head injury
> Diabetic people tend to forget sometimes
> A sickness like hypertension and if they don't use the treatment they can become like this

Other non-disease attributions are also apparent, frequently centering around affective issues. These responses were coded as “worries”:

Worries and children - they don't show respect, they are lazy and don't work
It is worries about grandchildren
Worries because he can't give his wife sex
It is nerves, may be due to worries about the children

In many of the semi-structured interviews Langa informants raised affective issues, a domain poorly covered in the DECO (Lenger, de Villiers & Louw, 1996).

However the majority of Langa informants (64%) see forgetfulness not as a disease but as a consequence of growing old:

It is not a sickness, just the age
The mind changes when you grow old
Simply an age-related problem
Just a natural thing

This is somewhat paradoxical given that 59% of Langa informants felt that forgetfulness was atypical in old age (see Table 2). This response set discrepancy may suggest that the concept of "old age" is both used and understood ambiguously among informants.

When talking about old age, 9 Langa informants used the phrase
"becomes like a child" when responding to the semi-structured questionnaire:

When they are old they become like a child
There is a saying that when people become old they become like a child
When you are getting old you talk to yourself, and then you lose your memory; become young again, like a child

Interestingly, the “phrase becomes like child” has been noted as a colloquial description for a dementing person used in both Chinese culture (Ikels, 1998) and Aboriginal communities (Pollitt, 1997).

Among Bothasig respondents, 44% do not perceive memory loss to be a disease. The majority of these (65%) see memory loss as being due to old age:

> Forgetfulness is a way of life for the elderly; its not a sickness or else you can go to a doctor
> Not really a disease - just getting old and tired

Certain of these responses convey a sense of forgetfulness as being a natural event:

> Its just a process of life
> Just normal decline
> Forgetfulness in old age is normal

The second half of the Results now follows. These data go beyond impressions of memory impairment and cognitive decline to explore perceptions of cognitive disturbances and disorientation in the elderly.

4.4 PERCEPTIONS OF DEMENTIA: THE CLINICAL VIGNETTE

The Bothasig informants (*n*=75) and cohort of Langa participants (*n*=24) were presented with a clinical vignette and a series of questions. The questions focus on pronounced cognitive disturbances rather than cognitive decline or memory loss, as do the preceding questions in the semi-structured questionnaire, and as such are designed to access beliefs and perceptions around dementia-like symptomatology.

4.4.1 The nature of the vignette

The clinical vignette was intended to portray an elderly lady exhibiting gross dementia symptomatology:

> It is early in the morning. About 5 'o' clock. On your way to work you meet an elderly lady dressed only in underwear. You start wondering about this situation. At last you decide to have a closer look and help. It is then that you realize that this elderly lady does not know where she is. She is very confused. The only thing she can remember is that she is from Pinelands.

The character in the vignette is disorientated, memory impaired and inappropriate. Although such cognitive disturbances conform with florid dementia-type symptomatology, other interpretations are possible. Four questions follow where the informant is asked to provide a possible cause for the character's behaviour, a suitable course of action, a comment on how people with similar problems can be helped, and finally what they believe another person would do in the same situation.

4.4.2 Comparison of Langa and Bothasig responses to the clinical vignette

For each of the 4 questions following the administration of the vignette, the methodological concerns and coding issues are explained. Verbatim responses are provided to further illustrate the nature of the data summarised in the tables. All 4 questions were open-ended and, where indicated, multiple responses were generated. Tabulated responses are therefore represented as percentages since certain respondents gave more than one answer.

4.4.2.1 Question 1: "What do you think is happening to this old lady"

Between groups, the widely different attributions regarding the cause of the character's behavior suggests significantly different approaches to understanding and describing dementia-like symptomatology. These attributions are summarised below in Table 10:

Table 10: Response to the question: "What do you think is happening to this old lady?"

	Bothasig (%)	Langa (%)
old age	6	17
disease process	19	0
senile/Alzheimer's	23	0
memory loss	31	8
violent assault	2	11
witchcraft	0	14
psychosocial problems	3	11
mentally ill	14	33
other	2	5
Responses (n=)	*107*	*36*

The typologies in the table above represent a process of ordering a multitude of diverse qualitative responses and certain response typologies cover a broad domain of answers. For example, “disease process” in Table 10 includes the following responses:

> She is sick
> A turn of some kind; perhaps she has been unwell and forgotten to take her medicine
> Probably sickly…maybe a stroke or heart attack
> A problem which needs to be diagnosed by a doctor

The typology “senile/Alzheimer’s” was coded where the respondent specifically used these terms (neither of these terms were cued by the interviewer). The category “mentally ill” naturally emerged from the data due to the frequency of Langa respondents who employed this phrase. Within Langa, variations on the phrase “mentally ill” included:

> She is mentally unsound
> She has a nervous breakdown

The translator who assisted in gathering the Langa data elaborates responses such as “mentally ill” to mean “she is mad”. Bothasig responses falling into this typology include the following:

> She is losing her mind
> Sounds like she’s having a mental problem of some kind

The category “psychosocial problems” includes responses covering affective- and anxiety-type disorders such as “an emotional problem” and the Langa concept of “worries”, which is related to anxiety.

Finally, the coding category “other” is employed for the response “I don't know” or “I can’t say”, or, in one instance, where the response was unclassifiable: “More peculiar than normal aging - I do not believe in witchcraft”.

In terms of response frequencies (refer to Table 10 above), 31% of the Bothasig group see memory loss as the reason for the old lady’s behaviour, while only 8% of Langa respondents employ this attribution. Over 40% of the Bothasig group attribute the character’s behaviour to a disease process with 23% of these informants specifying either senility or Alzheimer’s’ disease:

> She is either senile or has had a stroke
> She is old and confused - probably Alzheimer’s

This is in striking contrast to the Langa group where *no* specific attributions of disease were made. However, certain Langa responses do indicate an understanding of medical causation. Consider the following Langa attributions which point to a generic organic deficit:

> Something is wrong with her, her mentality, a mental illness, her brain is not working properly (coded as “mentally ill”)

> More peculiar than normal ageing - I do not believe in witchcraft (coded as “other”)

> A mental illness - her brain is not working (coded as “mentally ill”)

33% of Langa respondents described mental illness as the causal agent. To re-iterate: the translator used for the Langa data collection elaborates “mentally ill” (Xhosa: *ukuphambana)* to mean psychopathology as in “she is mad”. 14% of the Bothasig group employed a similar attribution. Attributions of “madness" include the following:

She may have escaped from a mental home (Bothasig)

She obviously has a mental problem (Bothasig)

There is something wrong mentally (Langa)

She is mentally unsound (Langa)

11% of Langa responses pointed to violent assault, such as rape or robbery, as the prime attribution:

She has been mugged or drugged or raped; she is in shock

Witchcraft was provided as the attribution in 14% of responses:

I will say that if it is a naked lady, then it is a witch

Similar responses were provided in combination with other suggestions, with the witchcraft theme attributed to others.

Could be an age related problem - many will say it is witchcraft - but mostly it is an age-related problem, as a person gets older, they get like that (coded as "old age" and "witchcraft")

I think it is being forgetful, but others think she can be a witch, that the *cage* dropped her somewhere (coded as "memory loss" and "witchcraft")

The notion of the "cage" was frequently mentioned by Langa informants in connection with witchcraft. The translator who assisted in gathering this data describes the cage as magical flying vehicle used by witches at night for transport. The cage supposedly drops the witch in early morning so that she may enter into someone's house to perpetrate evil. This belief is apparently common in rural areas such as the Transkei, an

area from which many Langa residents originate. If we consider the phrasing of the clinical vignette, it becomes apparent that the scenario inadvertently conforms with this mythology around the witch and her cage-like transport.

Unsurprisingly, there were no attributions of witchcraft among Bothasig respondents, and only one response covered violent assault.

Overall, these results indicate that whereas Langa respondents have employed diverse attributions, the majority of Bothasig respondents specified either a disease process or memory loss. It would appear that Bothasig residents are drawing on a medical model of causation to speculate on the character's behaviour. The Langa attributions reveal that different aspects of the scenario have been attended to and that although a few Langa respondents indicate attributions of physical illness, these respondents are in the minority.

Langa respondents appear more likely than Bothasig respondents to be attuned to the psychotic nature of the character . Such perceptions may reflect the social realities of their community where, for example, substance-induced delirium may be more commonly encountered than in Bothasig.

4.4.2.2 Question 2: "What would you do in this situation; what would be your response?"

Coding for Question 2 was not problematic as the categories emerged clearly from the data. The category "mental health professional" includes psychologists and social workers, while "medical" covered responses such as calling a doctor or taking her to hospital. The response frequencies are presented in Table 11 below:

Table 11: Responses to the question "What would you do in this situation; what would be your response?"

	Bothasig (%)	Langa (%)
police	47	37
my home	5	15
clothe her	10	26
question her		4
mental health professional		7.5
medical	36	7.5
old age home	1	
other	1	3
Responses (n=)	*111*	*43*

47% of Bothasig respondents and 37% of Langa respondents reported that they would manage the situation by first taking the elderly lady the police station. This statistic is interesting given that only a small percentage of either group attributes her behaviour to violent assault or crime (see Table 10). These figures suggest that regardless of how the character's plight is interpreted and what attributions are made, the police service may represent a gatekeeper or conduit to other resources, including medical.

Bothasig respondents would call the police for a variety of reasons:

> I would take her to the police - she might be a missing person
>
> Call the police, give them my number, and then follow-up later

Responses coded as "police" were often combined with other suggestions:

> I would take her to a hospital or old age home. Then I would call the police
>
> Take her to the police station after giving her my shirt

Take her to the police station to see if she's reported missing - also phone the hospital to see if she escaped

The relatively high number of responses from Bothasig (*n=111)* is based on the large number of combination responses. For example, 22 out of 75 informants combined "police" with "hospital", as the above responses demonstrate.

36% of Bothasig informants would respond to the character's plight by taking her to a hospital or medical practitioner:

Take her to the nearest hospital

No Bothasig respondents felt that a social worker or psychologist would be an appropriate course of action.

Langa respondents were more likely to provide a compassionate response than Bothasig respondents. Given that she was naked and distressed, their first course of action would be to clothe her (26%) or take her to their homes (15%):

I will take her to my house, clothe her, make her comfortable and find out how I can help her

37% of Langa responses combined these compassionate responses with taking the elderly lady to the police station for further assistance. Langa informants appear to be sensitized to the indignity and suffering inherent in the depicted scenario:

Try to find a blanket, put it on her and call the police
I will clothe the person and take her to a police station
Can help cover her up and take her to the nearest police station

Paradoxically, the majority of Bothasig informants would not respond according to their original interpretation of the situation. Only 30% who attributed the character's behaviour to a disease process or Alzheimer's disease would take her to a hospital or doctor as the first course of action.

4.4.2.3 Question 3: "How can people like this be helped in our society?"

The coding category "old age home" (see Table 12 below) includes responses such as:

> Put them in a home to be watched and taken care of
> She must go to a nursing home
> In an institution or an old age home

Several responses within the Bothasig group included combination of, for example, old age home and mental institution. In these cases it was decided to code both responses as they constituted different themes.

Responses such as the following were coded as "institution":

> She must be placed under professional supervision
> She must be institutionalised where they have constant supervision
> If it is a recognized disease she should be institutionalised

The coding category "medical" includes all responses referring to doctors, hospitals, and medical and pharmaceutical treatment. "Mental health professional" is a response category covering responses such as:

> A psychologist or psychiatrist must do tests

The frequency of the respective responses is summarised in Table 12 below:

Table 12: Response to the question "How can people like this be helped in our society?"

	Bothasig (%)	Langa (%)
old age home	25	47
institution	15	
medical	38	13
mental health professional	6	7
home care	13	13
don't know/ no answer	3	20
Responses (n=)	*89*	*30*

25% of the Bothasig sample and 47% of the Langa respondents felt that the old lady should be sent to a place of safety, such as an old age home, or an institution specialising in the care of the elderly. Typical are the following Langa responses:

> They need a place of safety, where they will be well looked after
> There must be a home built for them
> Take her to an old age home where she can be observed

Certain Langa respondents provided combination answers that were coded according to both categories:

> The social workers should take this up and these people should be taken into the old age home (coded as "old age home" and "mental health professional")

Bothasig responses frequently combined the suggestion of old age home with that of an institution:

> They should be placed in homes for the aged or a mental institution

38% of Bothasig respondents believe that a medical intervention is the best way to help people such as the character in the vignette. These responses indicate an implicit trust in the expertise of doctors and a willingness to defer responsibility to them:

> The doctor must put them on medication - or whatever he decides
> Depending on the diagnosis, special care is warranted
> I think there is medication, but no cure
> I don't know what's wrong with her, but doctors can find out

13% of Bothasig respondents felt that home care provided by relatives was more appropriate than a medical intervention:

> The children must look after them, must not put them in a home
> The family itself must take a greater interest
> They can't be helped, my uncle had Alzheimer's and all we could do was look after him

4.4.2.4 Question 4: "What would others do in the same situation?"

In coding the responses to Question 4, the category "witch" covers responses that attribute witchcraft to the character's behaviour. The following Langa responses were coded as "witch":

> The people will say she's a witch
> They will take her as a witch

The category "laugh" covered responses that indicated other people would mock or laugh at the character. These responses were frequently linked with "ignore", where no assistance was provided for the character. Hence the following responses were coded according to both these categories:

They would probably just laugh at her and walk away

People don't understand - they might laugh or just ignore it

The category "assist" was coded when it was felt that others would help the character. "No answer" was coded where the respondent was unable to answer or responded "I don't know".

The response percentages to Question 4 are summarised in Table 13 below:

Table 13: Response to the question "What would others do in the same situation?"

	Bothasig (%)	Langa (%)
witch		41
laugh	14	3
assist	37	31
ignore	47	3
other/no answer	2	21
Responses (n=)	*98*	*29*

For both groups, informants believe other people would generally react differently from themselves in that there were relatively high proportions of responses indicating that other people would not assist the character: 47% of Bothasig responses centered around ignoring the character, while 41% of Langa responses would have ignored the character due to witchcraft. There is clear disjuncture between the helping behaviours described in response to question 2 ("What would you do in this situation?") and responses to question 4 which imagine the behaviour of another person.

It is possible that this discrepancy has arisen as the question is accessing unconscious attitudes that respondents are attributing to an imagined other person. This question asks the respondent to assume the position of another person and imagine that

person's reaction. The fact that respondents attribute to others behaviours different from the course of action indicated for themselves (see Table 10) may suggest that unconscious attributions are being accessed.

In light of the data presented in Table 13 it must also be considered whether responses to Question 2 indicate a social desirability response set where informants are presenting themselves in the best possible light. If that were the case, then the attributions accessed in Question 4 may reflect some of the less altruistic attitudes held by Bothasig respondents. The high percentage (41%) of Langa witchcraft attributions revealed in response to Question 4 is also suggestive of a social desirability response set, given that only 14% of respondents indicated witchcraft as the primary attribution. This notion is explored further in the Discussion.

37% of Bothasig respondents felt that other people would stop to help. 31% of Langa responses were similarly categorized as "assist", and these often constituted elaborate and well considered courses of action:

> Others might come together in a community meeting to organize a place where they will have psychologists and activities

> The government can build some houses for them then someone who is in trouble can be taken there

47% of the Bothasig sample believed that other people would ignore the old lady by either driving or walking away:

> They would stare and walk past - a lot of people don't care
> Think she is drunk and ignore her
> Probably ignore her - people don't want to get involved

Several responses were combinations along the following theme:

> Most people would laugh and just walk past

Many responses from both groups contained the themes of both assisting and ignoring, as the following response demonstrates:

> They would ignore her and drive away - but a lot would help

Probing around these responses revealed that these respondents believed that other people would be afraid of being mugged or hijacked if they stopped to help:

> Its too dangerous, they would just drive past

In the Langa group, 41% felt that other people would think the old lady was a witch and they would therefore not help her. By comparison, there were no witchcraft attributions in the Bothasig group.

Responses to this question provide the most evidence of witchcraft attributions among the Langa informants:

> The people will say she's a witch
> They will take her as a witch
> She fell from a cage, she is a witch - witches walk at night
> I will say that if it is a naked lady then it is a witch
> Some people will say she fell from a cage and say don't go there she is witch
> They will say why do you worry; she flies by night it is witchcraft

It might be hypothesized that witchcraft attributions are likely to be made by less educated individuals. However, this is not the case. Both the range of educational

levels, and the means years of education for respondents who mention witchcraft closely approximate the overall Langa range and mean educational levels.

The Langa respondents often demonstrate an interesting duality. Respondents who interpret the character as being either mentally ill, a victim of violence or simply old, frequently provide witchcraft attributions when considering how other people would react. This Langa response interpreted the character's situation in the following way:

> Someone was trying to rape her or she was mentally ill

Yet when asked to consider other people's reaction, the same respondent answered:

> Why should I worry about someone I don't know and maybe she is a witch and [will] come bewitch our family

Similarly, another respondent provided the following account of his reaction:

> I will get someone to call the police while I watch her

And yet believed other people would react in the following way:

> They will think she fell from the cage and say don't go there she's a witch

Yet many Langa responses demonstrated an appreciation of both witchcraft attributions and other medically framed understandings. Consider the following 2 responses:

> Some will say it is about witchcraft, she is a witch, but maybe she was robbed. I think because she is old and she was robbed so she forgets where she is. She could be sick, forgetful or old-age sickness.

> Could be an age-related problem, some people will say it is witchcraft, but for me it is an age-related problem, as a person gets older, they get like that

These responses indicate a synthesis of traditional and western modes of interpreting and describing illness. Cross-tabulating responses to Question 4 with that of Question 1 ("What do you think is happening to this old lady?"; see Table 10) shows interestingly that that of the 41% of Langa respondents who believed others would see the character as a witch, only 8% (n=1) attributed witchcraft as the reason for the old lady's behaviour. This suggests that Question 4 is accessing interpretations not accessed by Question 1.

4.4.3 Concluding comments

These results complement the data provided on forgetfulness and expectations of the elderly and further develop an understanding of cultural differences in viewing cognitive decline. The vignette was intended to focus on cognitive disturbances and confusion by portraying an individual exhibiting florid dementia-like symptomatology. Langa and Bothasig respondents provided distinctly different accounts of her behaviour and an appropriate course of action.

4.5 Clarification session with key informant

The presentation of the Results identified certain problematic terms which are unlikely to have conceptual equivalence across both Langa and Bothasig groups. In this regard, the interview with an educated Xhosa-speaking key informant proved invaluable. The interview took the form of an educational discussion around key areas of the Langa data which, it was felt, required elaboration and explanation. This interview data is presented according to the areas of discussion. Indented paragraphs reflect paraphrased information provided by the informant.

Illness

Bothasig respondents frequently linked signs of cognitive decline to "illness" such as medical diseases like Alzheimer's or senility. The informant was invited to clarify what constituted illness among Xhosa-speaking elderly people:

> The elderly can become *ukulupala*, which means they are forgetful, slow, and they misplace things. Later they might be disoriented, unable to recognize people or dates. However, this *ukulupala* is not illness; its is just aging.

It was queried whether a worsening of the described symptoms would then constitute a sickness:

> No, it is still not illness. It would rather be an extreme type of aging.

Langa informants made frequent use of the term "becomes like a child"; what does this entail?

> To become like a child means severe memory loss, not knowing basic things. The elderly person loses certain adult abilities, like urinating properly, dressing

himself, and knowing the street name of where he lives. This is severe aging. It is similar to the dementia we have discussed, but it is not considered illness. It is like *ukulupala,* but with childlike features.

Madness

The relationship between "madness" and "mental illness" was discussed:

> Madness is termed *ukuphambana* and this is like a mental sickness. Madness is anti-social behaviour; doing things an ordinary person wouldn't do. There is something wrong in the brain. Mental sickness is similar but is more short-term; it is a less extreme form of madness.

In western culture, there is often a negative stigma attached to people who are termed mentally ill or mad. However, in a community such as Langa, psychotic episodes (such as that exhibited by the vignette character) are understood differently:

> If I have a friend who for one reason or another goes off the rails, leaves his job for awhile, talks to himself, goes crazy, he may be like that for awhile, but it won't last. He can go back to his life and this experience may never happen again.

However, a prolonged psychotic disturbance is described differently to ukuphambana:

> There is insanity, which is very severe. This is termed *ukugula nqengondo* and is characterized by going off the topic and being circumstantial. This is a case for Fort England or Valkenberg.

Attempts to clarify the difference between *ukugula nqengondo* and *ukuphambana* was problematic, as the difference is often based on context and socio-economic factors. It

appears though that “mental sickness/illness” describes a continuum where *ukuphambana* is considered as less severe and *ukugula nqengondo* as very severe.

The relationship between family and the elderly person

Issues around family and the role expectations of the elderly person were clarified. Of interest was the idea that cognitive decline may be linked to the level of status held by the elderly person:

> The old person often has to adopt a subordinate role in the family. This will happen where the family is very poor and he has no control over his money. He may have to compromise and not be seen as the wise elder. This unhappiness can lead to quick aging, and nerves and irritability. This is ageing in a very bad way. This is not sickness, because in an affluent family such decline may not happen. In a more wealthy family he will be more independent, and will sit with the family by choice. Here symptoms of decline don’t occur so much.

Witchcraft and the cage

Langa respondents often mentioned “the cage” in connection with witchcraft attributions:

> The cage is like a balloon that carries the witch around. She travels naked and is invincible. She can see you but you can’t see them. They travel by night and are dropped of in the early morning. They then find clothes so they can carry out evil. In Langa there are many people from the rural Transkei; these people have brought with them their traditional beliefs. In Langa they meet more westernized people so they come to have both witchcraft and western beliefs after awhile.

4.6 Synoptic account of Bothasig responses

What are the expectations of the elderly?

Bothasig responses indicated overwhelmingly that "very little" was expected of their elderly relative around the house. Typical sentiments included "Whatever she feels like doing" and "What they like doing". A variation on these statements included the idea that "They should do nothing" or "As little as possible". Overall, respondents indicated that there were few role expectations attached to the elderly within their homes. Notably, respondents were frequently unwilling to elaborate, and attempts to probe generated only paraphrasing of the original answer. A minority suggested that the elderly person was expected to "look after grandchildren" or "help with the washing", although such responses were often qualified with "…only if she wants to".

With regard to money, elderly people were expected to retain control over their finances "until they die". Responses suggest that issues of money were often associated with personal autonomy: "They should manage money till they die; its important that they maintain control" and "It is theirs to do with as they want; each individual should decide for themselves".

How do members of this community see the relationship between forgetfulness and old age?

In considering why their relative is forgetful, the majority of Bothasig informants employ old age as the attribution. The content of these responses suggests that cognitive decline is both "normal" and "natural" for elderly people. Reference was made to "just normal decline", and "just a process of life". Overall, the notion that "when you're old you forget" appears throughout the Bothasig data.

The relationship between old age and cognitive decline is described in various other ways.

A mechanistic discourse was apparent in certain responses which indicate that in old age the mind "wears out like the body" and "we just wear out like machines". Thus forgetfulness is caused by "just old age; everything starts to wear out".

Cognitive decline was also related to issues of loneliness and boredom. Elderly people can lack "stimulation" and become prone to "boredom and frustration" and this may cause or exacerbate cognitive decline. The role of "lifestyle" was mentioned where "if they are lonely it affects them more than others who live with family and friends".

In spite of the numerous references to forgetfulness as being natural in old age, the majority of respondents felt however that forgetfulness was atypical amongst the elderly. This contradiction may be due in part to the ambiguous usage of the term "old age". Thus only *some* forget because "you get old and start becoming forgetful" while another respondent states that *most* forget because "old age makes them forgetful". This ambiguity was also evident amongst Langa respondents. This flexible use of "old age" in support of various opinions indicates that the expectations and implication of old age may vary considerably.

What is the relationship between cognitive decline and illness?

Half of Bothasig respondents (53%) felt that forgetfulness can constitute an illness, and the majority of these specified Alzheimer's disease or senility. Alzheimer's was also a frequent attribution in response to the clinical vignette. Old age itself implied notions of disease for certain respondents: "She's just old and getting senile like most old people".

The other half of respondents (44%) saw forgetfulness not as a disease but rather as a consequence of old age: “It happens to most people, doctors cant help that”.

Certain respondents indicated that forgetfulness and illness represent degrees of cognitive decline: “Forgetfulness due to old age, or perhaps if its really bad could be Alzheimer’s or senility”.

What disease attributions are made?

Disease attributions were made in response to most questions presented in the semi-structured questionnaire. A number of Bothasig informants seemed well informed regarding medical conditions implicated in cognitive decline. Overall, 42% of respondents used the terms senile, dementia or Alzheimer’s. Frequently these terms were presented in conjunction with other viable illness-related attributions such as strokes and Parkinson’s disease.

Several lay understandings of dementia were also evident: There was reference made to “calcification of the brain”, and “declining brain cells”. One reference was made to a genetic component: “Some people have the misfortune of genes that go wrong”.

Certain informants made reference to “old timers disease” which is a colloquial description for a dementing process: “It is what people call Old Timers - same as being senile”. It is also possible that term is a variation of “Alzheimer’s disease” given its phonetic similarity.

Other medicalised attributions were provided: “lack of vitamins”, “pneumonia”, and “diabetes”. “Stress and fatigue” was also proposed as an illness attribution.

How is severe cognitive disturbance viewed?

Responses to the vignette scenario generated a range of attributions focusing primarily on “illness” and “mental problems”. Responses varied from generic notions of “sickness”, “a turn of some kind” and “running a fever” to highly specific attributions of Alzheimer’s, stroke and heart attack.

The vignette also generated notions of mental illnesses such as “losing her mind” or “gone mad”. Responses in this vein were often unspecific: “…a mental problem of some kind”. One respondent noted that “a psychologist or psychiatrist must do tests” while others felt that a “mental institution” was appropriate.
There appeared to be little relationship between attributions and subsequent course of action. Managing the situation showed that even where medical attributions were made, calling the police was chosen as the course of action.

Several informants incorporated compassionate responses with other courses of action. Thus “take her to the police or hospital” were frequently associated with “dress her first” or “give her my shirt”.

Respondents believed typically that other people would react very differently from the course of action indicated for themselves. Other people, it was felt, would predominantly “ignore” the character, or “laugh and walk away”. Possibly this suggests a social desirability response set as informants present themselves as more altruistic than others.

4.7 Synoptic account of Langa responses

What are the expectations of the elderly?

Langa respondents indicate overwhelmingly that elderly relatives are expected to assist the family by performing household tasks. Duties were described commensurate with the elderly person's abilities: washing (dishes/clothes); gardening; cleaning (sweeping/dusting); safe or small things; knitting or sewing; and tidying up.

With regard to money, 57% of the Langa respondents said that they would limit their relative's financial independence. The reasons for this varied. Some respondents felt that the elderly person was not capable of managing their own money: "She often puts her money where it becomes lost" and generally "Old people will forget to look after money". Other respondents felt that they were better able to look after the elderly person's money: "The children should help" or "The grandchildren often take over". Safety issues were also proposed: "It is dangerous for them alone".

In contrast , a portion of the Langa respondents (34%) felt that financial independence should not be limited: "If they want to handle their money, there should be no limit". Elaborating on this sentiment, others felt that "as long as she can manage". It was recognized that in principle, financial independence should not be limited although this depends on whether "she's still clever" or "whether they become forgetful".

How is the relationship between cognitive decline and old age viewed in this community?

Forgetfulness is seen by the majority of informants as inevitable in old age: "the older they are, the more they forget." In many cases, it appears as if old age implies forgetfulness: "when old people reach a certain age, they forget". A number of

respondents also interpret the cognitive disturbance exhibited by the vignette character in terms of “simply old age”.

Paradoxically, forgetfulness is not seen as typical in old age. Only some elderly are forgetful, due to a range of factors, including health issues “Not all of them are forgetful, on depends on their health,” and worries “Some people have worries”. Notably, a high proportion of these respondents were unable to provide a reason for their opinion.

Ambiguity was evident in the use of “old age” as a causative agent. Whereas “old age causes forgetfulness” for some informants, others opine that “Only a few forget - it’s the old age”.

Overall, across the semi-structured questionnaire, Langa respondents provide a range of attributions in clarifying the link between old age and cognitive decline. In response to certain questions, there is a cause-and-effect relationship between old age and cognitive decline; in response to other questions cognitive decline is attributed to a range of causative factors, including health issues, and “worries”.

How does the concept of ‘worries’ relate to cognitive decline?

The concept of “worries” was frequently mentioned by Langa respondents. “Worries” are frequently associated with the children or grandchildren of the elderly person. Certain respondents perceive forgetfulness as being caused by “worries” where perhaps “children neglect their elderly”, or “the young people are causing problems”. The key informant provided some clarifying information in this regard. The frequent association of worries with inter-generational conflict involves issues of status. In cases where worries are linked to “the children don't show respect” the key informant opined that the aging process will be exacerbated: “Unhappiness can lead to quick aging, and nerves and irritability”.

Worries can be caused by a range of other problems, for example "her husband died and she couldn't bury him because of money problems" and "Worries because he can't give his wife sex". These worries, it was felt, can cause some elderly people to be forgetful.

Worries were not mentioned in connection with the clinical vignette, suggesting that "worries" is not associated with cognitive confusion or psychotic-like presentations.

What is the relationship between old age and illness?

The majority of Langa respondents (64%) felt that forgetfulness was not evidence of illness. Forgetfulness is thus "not sickness, its just the age" and is "simply an age-related problem". The notion of *ukulupala* was provided by the key informant to describe an elderly person who exhibits a range of cognitive deficits that, even when severe, are not framed within a discourse of illness. Supporting this notion is the 17% of responses attributing the vignette character's behaviour to old age: "An age-related problem; as they get older they get like that". Certain respondents described severe cognitive impairments in terms of "bad aging" or "severe aging" with one informant specifying "It is not a sickness, just the age".

What are the notions of illness in this community?

Attributions of illness were raised in response to several questions. Stating that forgetfulness was evidence of disease, attributions ranged from vague descriptions of "an illness, I am not sure what kind" to "a disease which goes in the body system and then affects them". Other more precise attributions were evident. Mention was made of causative agents such diabetes, blood pressure, and hypertension. It was also suggested that forgetfulness may be related to head injury caused by "stick fights", or was due to

alcohol abuse. Responses such as these show that a medicalised lay discourse around illness exists in Langa.

The concept of illness appears to have ambiguous meanings within this community. Illness is described by some informants in terms of highly specific conditions such "An illness caused by sugar diabetes, high blood pressure or possibly head injury". Others appear to disregard notions of illness entirely by seeing cognitive decline as "just a natural thing", while certain informants have not considered issues of illness: "I don't know, maybe just old age". Furthermore, physical illness is distinguished from mental illness, which refers to "problems in the mind". Notions of mental illness are discussed below.

What is understood by mental illness?

In response to the vignette, the largest response category covered notions of "mental illness" as in the character in the scenario is "mentally unsound" or "there is something wrong mentally". The original Xhosa phrase for these concepts is *ukuphambana* which has been rendered into English as "mentally ill". This is perhaps misleading as ukuphambana is not considered as illness but rather as a temporary psychotic episode. The key informant notes that such an episode is neither stigmatized nor viewed as illness. *Ukuphambana* is also used casually to describe someone who is being silly or thoughtless.

The key informant noted that a prolonged psychotic disturbance is described differently to ukuphambana. *Ukugula nqengondo* refers to insanity which is considered very severe; in such cases psychiatric referral is appropriate.

Mental illness is used also to refer to situations were "the brain is not working properly" which may suggest an understanding of an organic condition.

What does it mean to "become like a child"?

No mention was made of dementia, but colloquial responses such "becomes like a child" relate conceptually to this medical term. Typical here is the notion that "their minds get looser and they become like children" and that "when they are old they become like a child". There is evidence that such notions are part of folk wisdom: "There is a saying that when people become old they become like a small child". Notably, this discourse is not framed within a concept of illness. The key informant used to clarify phrases such as "becomes like a child" described how in Xhosa culture such a person is a *ukulupala* which implies an elderly person exhibiting a range of cognitive deficits including memory loss, disorientation and impaired recognition of people and places. Even pronounced cognitive deficits are not perceived as illness, but rather, as the key informant explained, as "bad aging".

What are the range of attributions around witchcraft?

The vignette generated numerous witchcraft attributions among the 30% of Langa informants who used this term. Most attributions of witchcraft emerged when the respondent was asked to consider how other people would react. A number of respondents suggested that other people would "say she's a witch" and therefore ignore her. Witchcraft responses were frequently presented in conjunction with other responses, demonstrating a duality of western and witchcraft beliefs. This response epitomizes these dual understandings: "Some people will say its witchcraft, but for me its an age-related problem".

There was no correlation between witchcraft attributions and educational levels. Both highly educated informants (more than 11 years of education) and those less well educated (7 years or less) provided attributions of witchcraft.

Interestingly respondents who spoke of witchcraft in connection to how others would react, gave other attributions as the course of action indicated for themselves. This was typified by a respondent who would have asked others to call the police while watching over the character; other people it was felt would say “don’t go there, she’s a witch”.

Frequent mention was made of the “cage” is relation to witchcraft. The key informant used in clarifying the Langa data explains that the cage is seen as a form of transport used by witches traveling by night. In this regard, the phrasing of the vignette scenario inadvertently conforms with the mythology around the “cage” used by witches for transport. Hence “most people would say she is a witch who fell from the cage” and “she flies by night, it is witchcraft”.

CHAPTER 5: DISCUSSION

The Discussion pursues the two central aims of this study: Firstly to elucidate perceptions of memory impairment and dementia in the elderly by considering Bothasig and Langa responses to the semi-structured interview. Secondly, to examine the implications these data have for key areas of the DECO informant questionnaire.

The Discussion is therefore divided into two main areas. In the first, the data presented in the Results are discussed, and several key themes are identified:

5.1 Expectations of the elderly

5.2 The ambiguity of old age and normality

5.3 Pathologizing forgetfulness

5.4 Discourses around ill-health

5.5 Mental illness and the elderly

5.6 Folk discourses around old age and illness

5.7 Responding to cognitive disturbance

The second half of the Discussion, presented as Chapter 6, considers the DECO questionnaire and explores possible modifications in light of the data provided by the Langa and Bothasig respondents.

5.1 Expectations of the elderly

How are elderly people seen in these two communities and what is expected of them? Differences between Langa and Bothasig are immediately apparent. Whereas Langa elderly are expected to remain active in their support of the family, by performing household chores, Bothasig elderly are expected to occupy themselves as they see fit. On the surface such differences are hardly surprising. Socio-economic imperatives in the Langa community may necessitate the elderly having a more prolonged and active work life than in Bothasig, where notions of retirement are more prevalent. Prince reflected that: "Different cultures may place different demands on their oldest members, and may have different expectations of role performance. These demands may be greater in developing countries where…there is little notion of retirement" (1997, p. 4). By contrast, the responses from the Bothasig informants indicate that retirement is the norm for elderly people.

Elk, Swartz & Gillis (1983) conducted a psychosocial profile of Coloured elderly living in Cape Town. Although not concerned with either of the two communities examined in this study, their work provides some interesting comparative data. Strikingly, these researchers found that 87% of their respondents played an active role in household management, and that such involvement "contributes to feelings of satisfaction and self-esteem" (1983, p. 1020).

With regard to money, there were once again significant between group differences. 57% of Langa informants felt that, for a variety of reasons, it would be appropriate to manage their relative's money. Bothasig respondents indicated overwhelmingly (80%) that their relative should maintain control over their own money. The content of Bothasig responses (see Results) suggest that financial independence in old age is perceived to be a fundamental right.

In conducting research interviews in Bothasig, the question of money generated at times hostility or even a refusal to answer. Although it is not within the scope of this discussion to speculate on the nature of this anxiety,

Within the family structure typical of the Langa group, there are indications that the elderly person's self-hood may be significantly involved in the role he or she plays within the family. Moreover, although financial independence is noted as important to the quality of life for the elderly in the Bothasig group, "for many cultural groups such independence may represent a form of social isolation and may not be culturally appropriate" (Canino, Lewis-Fernandez & Bravo, 1997, p. 172). Bodibe identified a similar phenomenon in South Africa where the notion that "individuals should be self-sufficient, autonomous, independent…[is] often equated with mental health, but for an African such qualities would be regarded as extremely unhealthy" (1992, p. 151).

Given the socio-economic disparities between Langa and Bothasig it would be erroneous to attribute different expectations regarding the elderly to cultural factors alone. The key informant suggested as much by describing that, among the Xhosa, the role expectations of elderly persons as determined in part by the relative affluence of the family. Thus in poorer families the elderly person is expected to adopt a subordinate role while in an affluent home, the elderly person retains status and independence.

5.2 The ambiguity of old age and normality

It is apparent that notions of old age and normality are used ambiguously and often paradoxically by both Langa and Bothasig respondents. Old age is used by different informants to account for the beliefs that forgetfulness is typical, and atypical, among the elderly. Certain respondents stated that forgetfulness was not normal in old age, but that all old people forget. Such ambiguous usage may suggest that the concept of old age implies different capacities and abilities for informants. For some, old age is synonymous with cognitive deficits, both subtle and pronounced. Thus “she forgets because she is old” and “she is lost and confused because she is old”. Other informants see old age in neutral terms, as a variable confounded by health or social factors. In these cases “forgetfulness is caused by sickness in old age”. It is certainly apparent that “old age” refers to more than chronological age.

Many of the questions put to informants pursue the question of what constitutes normality in old age. Within Langa there is evidence that both subtle deficits, such as forgetfulness, and marked cognitive decline, are viewed by many informants as a normal feature of the aging process. The concept of old age thus incorporates a range of behaviours within a discourse of "normality". However, the normal aging process may be evaluated as 'severe aging' or 'bad aging' when cognitive deficits are pronounced.

Bothasig informants, more attuned to a medical discourse, exclude from their definitions of normal aging pronounced symptoms of cognitive decline. Forgetfulness is attributed by the majority of informants to a disease process, such as "something serious like Alzheimer's" or possibly "calcification of the brain". Thus the question of what is "normal" in "old age" reveals at the same time cultural differences between groups, and significant variation in how these terms are constructed within groups.

Within Langa, the ambiguous usage of "old age" can be better understood by considering the notion of *ukulupala.* This term is used to describe an elderly person who exhibits cognitive deficits ranging from forgetfulness to gross cognitive disturbances. Notably, even when severe, such deficits are not considered as symptoms of disease, nor as evidence of abnormal aging. *Ukulupala* is a concept which permits a range of symptom- like behaviours within a definition of old age. Thus, the attribution "it is just old age" may incorporate the belief that she is just *ukulupala*. It is possible

also that Langa and Bothasig informants operate according to different value saliency scales when evaluating signs of possible cognitive decline, such as forgetfulness. Different value saliency between groups may result in different internal cognitive scales against which an elderly person's behaviour is evaluated. If this is the case then the Langa notion of *ukulupala* may imply tolerance of a wider range of behaviours within the understanding of "old age".

Clarifying cross-cultural definitions of normality is largely a futile exercise as agreement on what is "normal", "typical" or "usual" varies considerably. It is possible though to venture some concluding comments on this vexed issue. We can say that Langa and Bothasig employ different bandwidths of normality in constructing understandings of old age. Thus old age in Langa tolerates a wider range of behaviours within its definition of normal aging than do Bothasig conceptions of old age, which permits a more restricted range of behaviours. These generalized comments should not mask the significant variance within groups where informants from both Langa and Bothasig revealed conflicting and ambiguous notions of old age and normality.

5.3 Pathologizing forgetfulness

If discourses around normality differ between Langa and Bothasig communities, so do understandings of what constitutes abnormality.

The most notable statistical difference between Langa and Bothasig arises in response to the question of whether or not forgetfulness indicates an illness. 64% of Langa informants felt that this was not evidence of an illness, and of these, the majority (73%) stated that forgetfulness was a consequence of natural aging. Bothasig respondents were divided into those who felt that memory loss constituted an illness (53%), of whom 66% specified Alzheimer's disease; and those who felt that memory loss was not evidence of an illness, with 65% attributing old age.

Reflecting on these data, it must be questioned whether the term "illness" has conceptual equivalence for both groups. If this is not the case then apparent between-group differences are an artifact of a universalist concept "illness" imposed on a culture that employs this concept in different ways. However, there is considerable evidence that a variegated and sophisticated discourse around illness does exist in Langa as the data reveals attributions of illness in response to many of the interview questions.

It is therefore likely that these data reflect true between-group differences, in which case it can be concluded that Langa respondents are less likely than their Bothasig counterparts to perceive forgetfulness in terms of illness. By contrast, Bothasig respondents appear to *pathologize* memory deficits by applying medicalised labels and terminology.

These observations accord with the work of both Chandra (1994) and Richards & Brayne (1996). These authors proposed that the extent to which different cultures label symptoms of cognitive decline, such as forgetfulness, as pathological or normal for old age depends on "cultural expectations of the elderly" and that "some societies, particularly those of western industrialized countries, are more ready to pathologize disability than others" (Richards & Brayne, 1996, p. 384).

The literature also indicates that if conceptions of normal aging incorporate forgetfulness and evidence of cognitive disturbances then early signs of dementia may be tolerated as 'normal'. This possibility was highlighted by Rajkumar, Kumar & Thara in their dementia prevalence study in rural India. The authors noted that the community under study held expectations of the elderly that meant that "many potentially treatable sources of disability, including memory loss, are recognized or tolerated as part of normal aging" (1997, p. 705). Pollitt (1997) similarly noted that cultural definitions of normality can significantly affect whether dementing individuals are perceived as sick or not. The Langa data provides evidence that forgetfulness - the primary diagnostic marker for dementia - is not considered evidence of illness and is understood to be a largely benign consequence of aging.

It is hypothesized that this may reduce the likelihood that relatives will draw attention to their elderly relatives poor memory. Since memory deficits are both the earliest and most significant diagnostic marker of Alzheimer's Disease, a prevailing tendency to

normalize these symptoms could contribute to the observed under-estimation of Alzheimer's Disease in the Langa community.

5.4 Discourses around ill-health

Attributions of illness were provided by informants in response to a number of questions. Notably, a number of Bothasig informants understood memory impairments to be evidence of a disease process and this understanding was elaborated by employing a predominantly medicalised discourse. Overall, 42% of Bothasig informants referred to Alzheimer's disease or senility; in addition many indicated lay-conceptions of dementing illnesses by speaking of calcification, declining brain cells, and genetic factors. Other illness attributions were raised in connection with vitamins, diabetes and pneumonia. As a group, Bothasig suggests a profile of informants who are largely well informed regarding the possible medical causes of cognitive decline and gross cognitive disturbance.

Langa informants do not refer to Alzheimer's disease although their illness attributions are equally wide ranging, including references to head injury, alcoholism, diabetes and hypertension. It is, however, clear that Bothasig informants are better informed regarding Alzheimer's disease than their Langa counterparts. Bothasig residents are more likely to be exposed to popular media and westernized medical care that in all likelihood would have sensitised them to some degree to the existence of dementia.

However, perhaps a more fruitful area of comparison between the two communities is to consider the relative bandwidth, or range, of causation employed to account for cognitive deficits.

Langa informants present a more differentiated discourse around cognitive decline, employing a wider bandwidth of causation that includes concepts of worries, social stressors and witchcraft. This notion is supported by Ensink & Robertson who showed that in constructing the meaning of illness Xhosa families indicate a "multiplicity of illness beliefs" by combining "concepts and explanatory notions from indigenous, biomedical, psychosocial and lay systems" (1997, p. 141). Thus the various Langa attributions including diabetes, stick fights, mental illness, worries, witchcraft represent together a coherent and integrative model of possible causation to account for ill-health. Illness is viewed not purely in medicalised terms, but as involving factors from several aspects of the individuals life. Although Bothasig attributions include loneliness, boredom, and losing one's mind, the preponderance of medicalised attributions suggest that this is the primary mode of viewing and accounting for ill-health.

5.5 Mental illness and the elderly

Respondents from both groups proposed attributions of mental illness to account for the vignette character's behaviour. Such attributions were not made in response to previous questions around forgetfulness and cognitive decline.

14% of Bothasig respondents provided the interpretation that she was "losing her mind" or had "gone mad". Others suggested that a "mental institution" and "psychologists" were appropriate. Such interpretations are highly plausible given the nature of the character's behaviour; from a diagnostic perspective her behaviour conforms with a psychotic episode and from this perspective psychiatric care is certainly appropriate.

Attributions of mental illness constituted the highest response category among Langa informants (33%). It must be noted that equivalence cannot be assumed between the Langa and Bothasig concepts of "mental illness", and the comparative statistics presented in the Results are partly an artifact of the coding strategy employed. A more detailed examination of Xhosa notions around mental illness reveals that there is significant variety and richness around the usage of "mental illness".

In order to appreciate this, we must return to the original Xhosa word *phambana*, translated into English as both "mental illness" and "madness". Such a translation has

been widely used although "it is unclear whether semantic equivalence can be assumed" (Ensink & Roberston, 1997, p. 153). Furthermore, the nature of *phambana*, its course, duration and cause, appears to depend on a range of contextual factors. Schweitzer (1977), for example, recorded that a number of factors may be implicated in *phambana*: witchcraft, spirit possession, interpersonal conflict, and refusal to accept a calling form the ancestors. Ensink & Robertson concluded that "*Phambana* appears to be a general category encompassing a range of behaviours associated with severe mental illness of the psychotic type" (1997, p. 155).

5.6 Folk discourses around age old and illness

Even a cursory survey of the data reveals that multiple discourses exist around the relationship between old age, normality and illness. One thread weaving through these discourses is the Langa notion of "becomes like a child" to describe cognitive deficits associated with old age. This description involves the "mind getting looser" and points to the regressive nature of a dementing illness where the victim becomes dependent on family and loses many of the executive functions associated with adulthood. In this sense, this colloquial description incorporates several diagnostic features of dementia and thus amounts to a folk or lay understanding of the dementing process. It is important to note though, that the data shows that "becomes like a child" is not framed with a discourse of illness but is rather seen in terms of the aging process, albeit as "bad aging".

The notion that elderly people become like a child has been described by cross-cultural researchers in both China (Ikels, 1998) and Australian Aboriginal communities (Pollitt, 1997). Both these researchers recorded that “becomes like a child” is used to describe an individual, who from a western medical perspective, is suffering from a dementing illness.

Pollitt (1997) identified variations on this phrase in Torres Strait Islander communities. Mild to moderate dementia is seen as “childlike behaviour” and the individual exhibits “baby sense”. Ikels noted that such descriptions are based on cultural expectations of the elderly: “there is a traditional Chinese belief that in old age people frequently return to a childish state” (1998, p. 272). A Langa informant similarly alludes to this cultural expectation: “There is a saying that when old people become old they become like a small child”.

Ikels reported also that “Even strange public behaviour, if it is not disruptive, will be excused on the grounds of childishness” and that commenting on such behaviour an informant responded “that's how old people get” (1998, p. 273). It is interesting to speculate whether these culturally framed expectations relate conceptually to the Langa concept of *ukulupala,* an understanding that incorporates and tolerates a wide range of behaviour as simply “old age”.

It is striking that most Bothasig informants employ a medicalised discourse when discussing old age and illness. There is little evidence of folk discourses beyond the occasional reference to “old timer’s disease”. On one level it is not surprising that a westernized, urban community, with good access to health care, is likely to view cognitive deficits in old age from a medical perspective. Bothasig respondents were for the most part well informed regarding dementia, and readily employed a medical discourse when accounting for their opinion that cognitive deficits can be evidence of disease.

However, another hypothesis can be advanced, one that allows us to consider the Langa folk understandings at the same time. It is possible that the westernized medical discourse employed by Bothasig informants has displaced more traditional, folk discourses around illness. This discourse acculturation is possibly a consequence of urbanization and the assimilation of western values. This hypothesis is supported by the fact that in Langa there is evidence of both folk understanding, typified by “becomes like a child”, and medicalised descriptions, for example, high blood pressure, that accord well with Bothasig attributions. The Langa community is heterogeneous in its degrees of urbanization with a mixed presence of 3rd-generation urban dwellers and recent arrivals form the rural Transkei. Consequently, the data show evidence of both folk and westernized discourses, provided at times by the same informant. Kim & Berry (1998) refer to this phenomenon as “dualism and parallelism” where one sector of a community or society is “westernized” and the other remains “traditional”.

An uncompromising relativist might describe a medicalised discourse as simply one cultural mode of responding to a profile of behaviours that are interpreted differently by someone operating from another cultural perspective. From this standpoint, "becomes like a child" and "dementia" are equally valid emic accounts of elderly people and their behavioural variations.

5.7 Responding to cognitive disturbance

The vignette generated extraordinarily rich data, especially with regard to the Langa attributes around witchcraft, and striking differences between the 2 communities were revealed.

Reflecting on these data it becomes apparent that many of the between-group differences are a result of the design and wording of the vignette. The clinical vignette was intended to illustrate a florid presentation of dementia-like symptoms and then to access respondent's perceptions and understanding of dementia. However, the highly ambiguous scenario was consistent with a range of other interpretations, including violent assault, a psychotic episode and witchcraft. Thus the marked differences in attributions between Langa and Bothasig reveal less about cultural constructions of dementia, than they do the social realities in these two communities.

Hence, attributing violent assault to the character's behaviour may be a realistic appraisal of the risk factors elderly people are exposed to in the Langa community. Bothasig informants overwhelmingly suggested a disease process or memory loss, which may constitute the most realistic attribution in terms of the social realities of urban Bothasig.

Nevertheless, the vignette proved most fruitful in accessing witchcraft beliefs among Langa informants. A number of informants attributed the character's state of cognitive confusion to witchcraft; nearly half of the respondents felt that others would interpret the situation in terms of witchcraft. The validity of this data would have been enhanced immeasurably had these attributions emerged in response to a more neutral vignette.

However, the content of the vignette inadvertently conformed to an existing Xhosa mythology around witchcraft and therefore may have primed respondents to talk about witchcraft. Reinforcing this is the fact that witchcraft attributions were only provided in response to the vignette and did not arise through any of the other interview questions. This only become apparent during the clarification session when the key informant was asked to explain the notion of "the cage", mentioned frequently by Langa informants. The key informant noted that to a rural Xhosa speaking individual it would appear as if the researchers were asking about witches, their conduct and mode

of transport. In spite of this methodological failing, the data around witchcraft is of considerable interest.

Only 14% of Langa respondents initially attributed the character's behaviour to witchcraft, and yet 41% believed that *other* people would see her behaviour in terms of witchcraft. The reasons for this discrepancy are unclear. It is possible that the data reflects a social desirability response set where informants were reluctant to associate themselves with so-called traditional beliefs in the presence of a white researcher. Thus the question of what other people might think of the situation allows the informant to express their beliefs around witchcraft while at the same time not identifying personally with such beliefs. This idea is demonstrated by responses such as "Some people say its witchcraft, but for me its an age-related problem."

Langa respondents often demonstrated an interesting duality. Respondents who interpret the character as being either mentally ill, a victim of violence or simply old, frequently provide witchcraft attributions when considering how other people would react. Frequently, Langa responses demonstrated an appreciation of both witchcraft attributions and other medically framed understandings thus demonstrating a synthesis of traditional and western modes of interpreting and describing illness. As we noted above, Ensink & Robertson (1997) discovered a similar phenomenon in their investigation into traditional Xhosa categories of distress.

Failure to consider the confounding effects of the vignette phrasing might lead an uncritical researcher to suggest that Langa informants may misinterpret dementia-like symptomatology in terms of witchcraft. This notion is refuted by the data regarding Langa responses to the character's situation which entail courses of action such as calling the police or providing comfort. Furthermore, half of Langa respondents felt that an aged care facility was an appropriate resource for such people.

Overall, in responding to cognitive disturbance in the elderly, Langa informants provide suggestions that accord well with the character's needs in the situation. Bothasig respondents provide a range of responses that, although statistically different in certain areas, constitute equally appropriate suggestions.

CHAPTER 6: IMPLICATIONS FOR THE CROSS-CULTURAL ASSESSMENT OF DEMENTIA

The data presented in the preceding sections regarding informant perceptions of cognitive impairments in the elderly has implications for the existing DECO informant questionnaire. The comparison of informant responses between the Bothasig and Langa populations suggests that certain key items on the DECO require modification if the questionnaire is to be suitable for use across groups. Certainly, the information from the semi-structured interviews and clinical vignette provides insight into how the DECO might be harmonized by incorporating differing cultural beliefs, socio-economic realities and appropriate language.

This discussion is then followed by an analysis of the DECO in terms of the etic-emic distinction, including some general reflections on cross-cultural dementia screening.

6.1 Proposed modifications of the DECO

In light of the data presented thus far, 4 key areas of the DECO have been identified as problematic for use in cross-cultural screening. These problem areas are discussed and modifications are proposed:

6.1.1 Activity Levels: Question 9

6.1.2 Access to appliances: Question 6

6.1.3 Management Of Finances: Question 8

6.1.4 Literacy: Question 11

6.1.1 Activity Levels: DECO Question 9

70% of the Bothasig group felt that their elderly relative should be able to do anything they like within the home, indicating that, in the majority of cases, no specific role expectations were attached to the elderly. In contrast, 75% of the Langa group expect their elderly relative to support the family with menial tasks and duties. These between-group differences reflect both differing socio-economic conditions within the two communities, as well as differing cultural expectations regarding the elderly.

These data have important implications for Question 9 of the DECO which asks about changes in activity level:

> 9. Apart from difficulties due to physical problems, has there been a reduction in his/her activity level?

The interpretation of this question is based on cultural expectations of the elderly and value saliency scales around daily activities. Thus, if the informant believes that old people are not expected to do anything, as is the case with the majority of Bothasig informants, then they may report 'no change'. In this case, the informants' belief has obscured the difference between an individual who is dementing and one who is demonstrating reduced behavioural capacity in accordance with certain cultural expectations. If informants conflate these observations the discriminability of the DECO item would certainly be reduced.

A diagnosis of probable dementia must be accompanied by evidence of significant impairment of social or occupational functioning (Lezak, 1995); identifying the degree of such impairment is the intention behind Question 9 of the DECO. The question is also particularly important as it is the only item which assesses behavioural changes such as apathy (Lenger, de Villiers & Louw, 1996). However, "different cultures may place different demands on their oldest members, and may have different expectations of role performance. These demands may be greater in developing countries

where…there is little notion of retirement" (Prince, 1997, p. 4). Socio-economic imperatives in the Langa community may necessitate the elderly having a more prolonged and active work life than their counterparts in Bothasig. By contrast, the responses from the Bothasig informants indicate that retirement is the norm for elderly people. If this is the case, the attendant differing role expectations will produce skewed responses on DECO items exploring reduced activity levels.

Given the predominance of these beliefs in this population, the emphasis of DECO Question 9 on observed change in activity levels is problematic because the majority of Bothasig respondents expect nothing of their elderly. Commenting on relative decline in behavioural capacity thus becomes contaminated by the prevailing expectation that elderly people maintain, or should maintain, minimal activity levels.

Hendrie *et al* (1995) produced a seminal study comparing the prevalence of Alzheimer's disease between Nigerian Africans and African Americans. In considering their data, the authors noted that: "Since the diagnosis of dementia depends to a great extent on the determination that the cognitive decline has significantly interfered with social and occupational functioning, it is possible that the differing lifestyles of the elderly in the two communities may have led to a lower estimate of dementia among the Ibadan [Nigerian community]" (1995, p. 1490). These researchers recognized that differing lifestyles and concomitant behavioural expectations on the part of informants may confound ratings of dementia related symptomatology.

The majority of the Langa group have low expectations regarding their relative's behavioural capacities while at the same time expecting them to perform certain duties in support of the family structure. It is proposed that given these moderate expectations it would be difficult to accurately assess whether activity levels have changed in frequency or intensity.

This notion is supported when the data from the Langa group's actual DECO responses is considered. This data is summarized from the original study conducted by Lenger, de Villiers & Louw (1996): In responses to Question 9 of the DECO, which asks "Apart from difficulties due to physical problems, has there been a reduction in his/her activity level?", 84.7% (*n*=61) of Langa informants reported that activity level was "much worse". 7% (*n*=5) reported "not as well", while 8% (*n*=6) reported better or similar activity levels. With the exception of one other questionnaire item, this question has the highest number answering in the 'severe' category. Moreover, responses in the "much worse" category for Question 9 do not match with clinicians' diagnosis of probable dementia.

This distribution points to a ceiling effect in the data where Langa respondents evaluate changes more severely. Unfortunately the data from the original DECO study conducted by Ritchie & Fuhrer (1996) is not available for the purposes of comparison.

It appears then, that this item, lacks sufficient discriminability in this community. It is this researcher's contention that the behavioural expectations deriving from prevailing cultural norms within the Langa population render the DECO item on activity levels unsuitable for further use without modification. Moreover, Lenger, de Villiers & Louw (1996) note that 5 respondents out the 71 did not understand the question due to a combination of the way the question was phrased and the relative complexity of the terms 'reduction' and 'activity levels'. In addition, it is proposed that Question 9 may be problematic in Bothasig where interpretation of activity levels may be affected by the expectation that elderly people should maintain minimum activity levels.

Recommendations

The phenomenology of the Langa responses suggests that Question 9 should be modified to include specific examples of domestic activities that informants could evaluate. For example, rephrasing the question to: "Has his/her ability to do things around the house, such as cooking or cleaning, become worse over the last year?" may better incorporate caregiver's observations and thus increase the clinical usefulness of their observations.

The rephrasing of this question may also better suit the Bothasig population by specifying actual behaviours that the elderly person is certain to perform in their activities of daily living.

6.1.2 Access to appliances: DECO Question 6

The issue of cultural norms also pertains to Question 6 of the DECO, which is phrased:

> 6. In comparison with a year ago, how well is he/she able to use household appliances (washing machine, etc…)?

In their work screening for dementia with Aboriginal elders, Kaufert and Shapiro queried the "cultural appropriateness of cognitive functions and activities measured" and subsequently recommended that "situational variation may be controlled for by employing measures which evaluate cognitive function within the context [of] the respondents role, living environment and community culture" (1996, p. 279). They caution that informants may respond inconsistently when questions explore activities of daily living which are perceived as irrelevant to their role within the community or family. These comments are germane when considered against Question 6 of the DECO which asks the informant to rate the elderly person's ability to use household appliances, using the example of a washing machine.

No responses from the Langa group indicated that the use of appliances were expected of the elderly relative; the majority of respondents provided responses that indicated household duties around washing, cooking and cleaning.

Question 6 was devised to assess changes in functional capabilities and evolving behavioural deficits. The phrasing of the question explores the elderly person's use of household appliances and uses the washing machine by way of example. Given the nature of caregivers expectations of the elderly within the Langa community, and the probable limited access to luxury items, the question needs to be adapted in order to better assess the individuals functional capabilities.

Recommendations

Regarding Question 6 of the DECO, it appears that it would be more appropriate to specify a household appliance such as a kettle or toaster, which are more likely to be ubiquitous throughout both Langa and Bothasig households. The household appliance should also be applicable to both sexes. However, this question will remain problematic when applied to rural settings where there may be no electricity.

6.1.3 Management Of Finances: DECO Question 8

A significant percentage of the Langa group (16%) report that their relative is forgetful regarding money; this concern was mentioned by none of the Bothasig group. These data have important implications for Question 8 of the DECO which asks:

8. How well does he/she manage her money, for example doing the shopping?"

In the follow-up questionnaire, informants were asked "Should a person's financial independence be limited by their age?" The question of financial independence revealed notable differences between groups. Within the Bothasig group 80% (n=60) said that they would not attempt to restrict their elderly relative's financial independence, and that they would allow their relative to control their money until they died. By contrast, 57% (n=40) of the Langa respondents said that they **would** limit their relatives financial independence.

These different attitudes seem to emerge out of two differing models of cultural expectation. The Bothasig respondents seem to equate personal autonomy with financial self-determination, while Langa respondents indicated that elderly people are expected to relinquish control of money in keeping with the role expectations attached to them.

Information based on culturally mediated expectations, such as that provided by the DECO item under discussion, must be integrated with, and contextualized by, an understanding of the linguistic and socio-cultural factors that influence the data. Only once this is done can the researcher "clarify how to adjust diagnostic algorithms to local phenomenological diversity" (Canino, Lewis-Fernandez and Bravo, 1997, p. 172).

The phenomenological diversity evident in the Bothasig and Langa responses regarding managing money suggests that the content of Question 8 needs to be adjusted. The DECO was originally devised and standardised on a predominantly affluent Western population (Ritchie and Fuhrer, 1994) where financial independence for the elderly is considered normal and possibly a fundamental tenet of dignity in old age. This perspective predominates among the Bothasig respondents where elderly people are expected to manage their own money. In this context the DECO assumes that elderly people retain control over their money and thus any observed decline in their ability to do so may signify cognitive decline.

However within a non-Western context, such as that of the Langa informants, decline in the ability to manage money may be confused by the family's withdrawal of financial independence from the elderly person, for socio-economic or cultural reasons. Information provided in response to Question 8 of the DECO may thus be contaminated by the belief that elderly people should not control their own money. Moreover elderly people within the Langa community are less likely to be entrusted with money or financial autonomy as caregivers perceive their elderly relatives as incapable of responsibly managing financial matters. It may thus be problematic for relatives to provide an unbiased response to Question 8.

The issue of money may become especially problematic when applied to illiterate or rural populations where the ability to manage money and do shopping is not a typical daily activity. As Lenger, de Villiers and Louw (1996) noted, the efficacy of the DECO when used with illiterate or unschooled respondents remains uninvestigated.

Recommendations

Question 8 of the DECO explores the elderly person's ability to manage money to explore changes in executive functioning, capacities known to be compromised in dementia. As the preceding discussion has shown, issues around money may be significantly influenced by socio-economic and cultural factors and thus biased observations on executive functioning may result. Although this bias is not evident in the Bothasig group, an informant questionnaire of cross-cultural purposes requires that Question 8 be adapted.

The following is proposed:

Question 8: "Does your relative use money for shopping? If so, how well does he/she manage compared with a year ago?" If the individual does not use money, then the DECO item should be scored "better or the same" in keeping with Ritchie and Fuhrer's (1992) suggestion for scoring illiterate respondents.

6.1.4 Literacy: DECO Question 11

Although the DECO has been found to be free of the education bias associated with the MMSE, the original DECO screening instrument was developed for use with first world populations where an adequate degree of literacy was assumed regardless of education levels. This assumption cannot be made when employing the DECO in South Africa. The demographic data between the Bothasig and Langa demonstrates a high level of literacy for both groups of respondents (Bothasig 97%; Langa 95%). For the purposes of this study, literacy was defined as the ability to read and write. However, the Langa respondents have on average a Standard 6 education, or 8.53 years of schooling, which suggests that in fact literacy levels between the Bothasig and Langa are not equitable.

The issue of formal literacy assumes relevance when Question 11 of the DECO is asked:

> 11. And writing letters for business or to friends, does he/she do this as well as a year ago?

In the original pilot study, Lenger, de Villiers & Louw (1996) noted that this question proved problematic in 6 cases, although in only one case was the question problematic because of illiteracy. In the remaining cases the question proved inapplicable because

the elderly person had either always engaged in manual labour that did not require the writing of letters, or lived in a close community where he or she communicated verbally. These instances of inapplicability are likely to be amplified when Question 11 is applied to rural populations. Lenger, de Villiers & Louw further note that “The efficacy of the DECO when the informant cannot read or write and is entirely unschooled still needs investigation” (1996, p. 740).

In keeping with the recommendations of the original compilers of the DECO (Ritchie & Fuhrer, 1992), this item was scored “better or the same” in the Langa pilot study when the question did not apply to the elderly person. Certainly though, this question, and the associated issues of testing illiterate patients, raises methodological concerns. When used to screen populations that are predominantly illiterate Question 11 may best be omitted and cut-off scores adjusted accordingly.

CHAPTER 7: CONCLUSIONS

THE DECO RECONSIDERED IN TERMS OF ETIC-EMIC PERSPECTIVES

Medicine is in many ways free of the relativist considerations that pertain to DSM-IV diagnostic categories. For the most part, medicine covers a domain where disease entities are empirically verifiable realities independent of cultural context. However in the case of dementia, there are no reliable biological markers, no unequivocal medical tests, nor is there is a universal profile of dementia symptoms. In the case of Alzheimer's Disease, for example, diagnosis can only be made post mortem; until such time as autopsy can confirm the existence of pathological changes associated with the disease, diagnosis is termed "possible" or "probable". Diagnosis thus rests on interpreting symptoms, which the literature shows, are substantially shaped by cultural variables. The data from this study has shown too how symptoms common to both Langa and Bothasig are interpreted differently and attributed to different agents. For these reasons, adopting an uncritical universalist perspective when considering cross-cultural manifestations of dementia is certainly problematic.

The literature concerning cross-cultural dementia screening using cognitive batteries shows little evidence of any emic critique of the prevailing methodology employed by medical researchers. This should not suggest that such a critique is not warranted, nor that emic perspectives have little bearing on the project of global dementia epidemiology. The reason that etic approaches prevail is due solely to practical

considerations. With limited time and resources, researchers employ readily available and extensively used cognitive screening tools such as the MMSE, in spite of its widely demonstrated shortcomings. For similar reasons, the western bio-medical construct of dementia is employed as the primary nosological diagnostic category, and this is applied cross-culturally regardless of cultural variations.

The literature has however shown that cross-cultural researchers working with informant questionnaires are aware of these issues and have consequently endeavored to incorporate emic data within the translated instrument. It has been recognized that conceptual and construct equivalence can only be achieved through a detailed emic account of perceptions and attributions within the culture under consideration.

The data presented in this study was collected through reflection on the DECO, an informant questionnaire proposed for use in South Africa. Considering these data, it may well be queried whether it is possible to satisfactorily adapt the DECO for true cross-cultural equivalence. Given the methodological concerns implied when translating a psychometric instrument from one cultural and linguistic framework into another, harmonizing the DECO for use in South Africa is an ambitious goal.

The original Langa project (Lenger, de Villiers & Louw, 1996) adopted an etic-universalist approach in screening for dementia by assuming that the DECO could achieve conceptual equivalence through item translation alone. Although rigorous, the

linguistic translation failed to incorporate significant cultural differences between the Langa population and the original French sample used by Ritchie & Fuhrer (1992) in creating the DECO.

There is an undoubted attraction in adopting a universalist perspective in screening for dementia. Firstly, by employing a standardised instrument measuring a unitary medical construct, cross-cultural comparisons are possible. Cross-cultural comparisons may facilitate the identification of ethnic groups with significantly different prevalence rates of dementia thereby enhancing the search for dementia risk factors. Even where significant differences are not apparent, identifying prevalence rates is important for the purposes of health care planning. Secondly, the use of the DECO in a universalist manner was also motivated by a very real need to discover a means of screening for dementia in South Africa in a cost effective and efficient way.

However, from a relativist perspective the DECO project is called into question. The cultural differences evident between the Langa and Bothasig communities suggest that the DECO may require more than linguistic translation in order to achieve conceptual item equivalence. There are several fundamental areas of concern:

- There is considerable ambiguity in the usage and understandings around “old age”, “illness” and forgetfulness.

- Moreover expectations of the elderly vary widely between these two communities which pertains to DECO questions that require an evaluation of changes in daily activities.

- A further critical area of cultural variation is relative definitions of what constitutes behavioural normality or abnormality. Relativist researchers have shown how such definitions vary considerably between cultures - a striking fact given that Informant Questionnaires require a subjective appraisal of whether certain behaviours deviate from normal or not.

- The most significant area of concern, however, is the evidence that many Langa respondents view memory deficits as part of normal aging. There is therefore the risk that tolerating forgetfulness as normal may confound informant observations provided in the DECO. Thus, an informant who believes that memory loss is normal in old age may not remark on its decline in response to DECO items that explore this area. In community studies where these perspectives prevail, research has indicated that responses to informant questionnaires may be inaccurate due to this effect (O'Connor *et al*, 1989b).

The failure of the Langa study to incorporate these cultural factors indicates that inadequate attention was paid to developing a grounded emic account of Langa perceptions prior to translation. The areas of difference between the emic accounts of

Langa and Bothasig revealed in this study suggest that it is worth reconsidering the cross-cultural aspirations of the DECO project. There appear to be 3 main options available to future researchers.

The first is to use the DECO across cultures, the only adaptations being linguistic translation and slight item modifications as indicated in the Discussion. The DECO after all is framed in simple, non-ambiguous language that generally has conceptual equivalence across cultures. The advantage of this approach is that the DECO retains cross-cultural comparability. The significant disadvantage to such an etic approach is that cultural perceptions within certain cultures may affect scores resulting in either false positives, where the individual is incorrectly scored as dementing, or false negatives, where a dementing individual is incorrectly identified as cognitively intact. Clearly the risk of false negatives is a serious concern as the main purpose of the DECO is to identify cognitively impaired individuals who would benefit from further assessment.

The second option, advocated by radical emic researchers, is to develop a screening interview specific to a particular culture. The content of the interview is drawn from a grounded emic account incorporating cultural perceptions, attributions and key phrases used by members of the culture. While this approach is likely to be highly sensitive to dementia in that particular setting the drawbacks are the high costs involved in

development and standardization, and the limited applicability of such an interview for other cultures.

The third option is to incorporate these two approaches into a true derived etic thereby reconciling universalist pragmatics with relativist concerns. As such it is recommended that future studies in South Africa employ the DECO, translated into the target language, in conjunction with a grounded emic screening questionnaire (ESI). The ESI would constitute a culturally-attuned emic instrument where the discourses and understandings of, for example Xhosa-speaking people, are structured into questions around cognitive deficits in the elderly. This study has indicated several productive areas of inquiry for inclusion in the ESI. Given the folk discourse around old age and childishness, a likely item on this questionnaire would be to ask informants whether or not their relative "becomes like a child". This question exemplifies a "derived etic" (Kim & Berry, 1996) where a dementia marker is aligned with a culturally specific understanding. A further item for inclusion would involve asking informants if their relative is *ukulupala.*

The advantages of such an approach is that a true derived etic is achieved where cultural variance is reflected in the instrument, although not at the expense of its cross-cultural comparability. A further advantage, is that the ESI would provide collateral information to minimize the serious risk that the DECO may generate false negative results. Thus in any case where the ESI correlates poorly with the DECO, the

individual can be referred for more in-depth clinical assessment. In future pilot studies the discriminability of the DECO and the emic screening instrument should be assessed with Receiver Operating Characteristics (ROC).

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9. APPENDICES

9.1 The semi-structured questionnaire

The following questionnaire was administered to the both the Bothasig and Langa informants:

RESEARCH QUESTIONNAIRE

Your highest educational level : _____ Your age: _____Gender: M - F
Elderly relatives educational level : _____ His/her age: ____Gender: M -F
How are you related?:_____

1. Is your elderly relative forgetful?
If no, proceed to Q. 5
If yes: 1.1 What does he/she forget?

1.2 Anything else?

2. Why do you think _____ is forgetful?

3. Do you think all old people are forgetful, or only some of them?

4. Why do you think that it is so?

5. Do you think forgetfulness in old age is an illness?

If yes: What kind of illness?

If no: What is it then?

6. If your elderly relative became forgetful, would you take him or her to a doctor to find out what happened?

7. Up until what age would you worry about a person's poor memory?

8. If you wanted to know whether your relative was becoming forgetful, how would you go about finding this out; how would you test for it?

9. Should a person's financial independence be limited by their age?

10. What duties or responsibilities do you think an elderly person should have in the family?

Part B: Clinical Vignette

I would like you to give me your opinion on this story:

" It is early in the morning. About 5 'o' clock. On your way to work you meet an elderly lady dressed only in underwear. You start wondering about this situation. At last you decide to have a closer look and help. It is then that you realize that this elderly lady does not know where she is. She is very confused. The only thing she can remember is that she is from Pinelands.

Questions:

1) What do you think is happening to this elderly lady?

2) What would you do?

3) How can people with this problem be helped?

4) How do you think the general public would react to this?

9.2. The DECO

We would like you to tell us how your relative was a year ago.
The following questions ask about a number of everyday situations. We would like you to tell us whether in these situations he/she is doing about the same, not as well or much worse, than a year ago.

Put a cross in the square to show your reply :

	better or about the same	**not as well**	**much worse**
1. Does he/she remember as well as before which day of the week and month it is?	+	+	+
2. When he/she goes out of the house, does he/she know her way as well as before?	+	+	+
3. Have there been changes in his/her ability to remember her own address or telephone number?	+	+	+
4. In the house, does he/she remember as well as before where things are usually kept?	+	+	+
5.And when an object isn't in its usual place, is he/she capable of finding it again?	+	+	+
6.In comparison with a year ago, how well is he/she able to use household appliances (washing machine, etc…)?	+	+	+
7. Has his/her ability to dress or undress changed at all?	+	+	+
8.How well does he/she manage her money, for example doing the shopping?	+	+	+
9. Apart from difficulties due to physical problems, has there been a reduction in his/her activity level?	+	+	+
10. How well can he/she follow a story either on television, in a book or told by someone?	+	+	+

	better or about the same	not as well	much worse
11. And writing letters for business or to friends, does he/she do this as well as a year ago?	+	+	+
12. How well does he/she recall a conversation you have had with him/her a few days ago? Has this changed over the past year?	+	+	+
13. And if you remind him/her of this conversation, does he/she still have difficulty remembering it in comparison with a year ago?	+	+	+
14. Does he/she forget what he/she wanted to say in the middle of a conversation? Has this changed in the past year?	+	+	+
15. In a conversation, does he/she sometimes have difficulty finding the right word?	+	+	+
16. In comparison with a year ago, how well does he/she recognize the faces of people he/she knows well?	+	+	+
17. And how well does he/she remember the names of these people?	+	+	+
18. In comparison with a year ago, how well does he/she remember other details concerning people he/she knows well: where they live, what they do?	+	+	+
19. Over the past year, have there been changes in his/her ability to remember what has happened recently?	+	+	+

9.3 Letter to UCT Medical School Ethics Committee:

23 June, 1997

Professor P Folb
Chair: Research Ethics Committee
UCT

re: **Response to Ethics Committee**
TOWARD A CROSS-CULTURAL QUESTIONNAIRE FOR THE DIAGNOSIS OF DEMENTIA IN SOUTH AFRICA: A PILOT STUDY IN THE BOTHASIG AREA.

Thank you for your comments regarding my application to the REC Committee. I trust that the following points will provide some clarity:

1. Confounding variables of education and literacy are critical, as these can influence the validity of results. The study does not aim to control for these, but rather to include these factors in the analysis, to identify whether or not education and literacy effect the informants' responses. Thus, if the study demonstrates that these variables do in fact confound, then future work will entail modifying the DECO questions, and re-testing the questionnaire.

2. The proposed project is a pilot study aiming to contribute sound recommendations for the continued modification of the DECO, and thus provides only a partial contribution to the long-term goal of a final-draft cross-cultural questionnaire.

3. In order to develop a cross-cultural assessment instrument, extensive work will need to be done in standardizing across population groups. This task does not fall within the aims of the proposed study, which constitutes a thesis for submission in partial fulfillment of the requirements for a coursework Masters degree in Counselling Psychology.

Yours sincerely,

DAVID ALAN FAIR