WOMEN LIVING WITH HIV/AIDS:
A PHENOMENOLOGICAL INTERGENERATIONAL INTERPRETATION OF THEIR EXPERIENCES

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ABSTRACT

This study deals with the impact of HIV/AIDS on women living in chronic poverty. The question arises: Do we focus on their HIV/AIDS stories only or do we include their other lived experiences? This phenomenological study, on two sets of three generations of women infected and affected by HIV/AIDS and living in poverty, is an attempt at understanding the way the women experience their lifeworlds, not only their HIV/AIDS stories. One set includes a grandmother, her daughter who is living with full-blown AIDS, and her granddaughter, while the other includes a grandmother, her daughter and her granddaughter infected with HIV. The initial focus of the study was on the women's HIV/AIDS narratives. However as the study progressed, especially during the interviews, it became apparent that the women's generational poverty or chronic poverty was of greater concern to them than the HIV/AIDS that they were experiencing. Of the six participants, only one woman centred her life story on HIV/AIDS. This finding echoes other studies on HIV/AIDS among poor women: that chronic poverty is more threatening to the women than the risk or reality of AIDS.

As a phenomenological researcher my aim was to focus on the participants' own interpretations of the studied phenomenon. However, this was inadequate in accounting for the role that social structures play in shaping and informing the women's subjective consciousness and experience. For this reason, I used feminist ideas to understand and interpret the women's patriarchal experiences.

This thesis is dedicated with loving memory to my
late husband
Donald Miselo Chisaka,
***whose quiet intellect lives on in Kabwela and Lwamba*.**

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It is with the above expressed gratitude in mind that I take responsibility for the interpretation of the life stories of the women (and men) presented in this study, including the conclusions arrived at.

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LIST OF ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ARV	Anti-retroviral
CADRE	Centre for AIDS Development, Research and Evaluation
CBO	Community-Based Organisations
CD4	Cluster of Differentiation 4
CPRC	Chronic Poverty Research Centre
GHDF	Grahamstown Health Development Forum
HIV	Human Immunology Virus
HSRC	Human Sciences Research Council
ICW	International Community of Women Living with HIV/AIDS
NGO	non-governmental organisation
NRF	National Research Foundation
PWA	People with AIDS
RA	Rheumatoid Arthritis
TB	Tuberculosis
UNAIDS	United Nations Joint Programme on HIV/AIDS
UNDAW	United Nations Division for the Advancement of Women
UNFPA	United Nations Fund for Population Activities
UNICEF	United Nations Children’s Fund
UNIFEM	United Nations Development Fund for Women
WHO	World Health Organisation

CHAPTER 1
AN INTRODUCTION TO THE STUDY

1.1 Introduction

This study looks at the lifeworlds of two sets of women. Each set consists of three generations of black South African women living, in a figurative sense, on society's margin. The suffering of these women is compounded by the negative effects of HIV/AIDS. The rationale behind this research design is that the majority of poor Africans live in multigenerational family units, which are predominantly headed by women (Ferreira, 2004: 6). This particular family set-up is more prevalent now than ever before, because of the AIDS pandemic. In addition, statistics in sub-Saharan Africa show that women are increasingly more infected and affected by AIDS than men (UNAIDS/UNFPA/UNIFEM, 2004: 2). Furthermore, according to the UNAIDS/WHO (2005: 20) report on the prevalence of HIV infections, Southern Africa remains the epicentre of the global epidemic. While the statistics are useful indicators of the gravity of the situation, they offer limited insight into the experiences of individuals living with HIV/AIDS. In addition, they offer little or no insight into the effects this has on those directly caring for AIDS patients. As one HIV-positive woman so aptly says, "statistics don't mean anything. Behind every figure there's a person with feelings that hurt, that cries. But we are so wrapped up in the statistics" (Cardo, 1999: 165). This study therefore focuses on the life histories of two sets of women living with HIV/AIDS and finding themselves in a household consisting of three generations (grandmother, mother, daughter).

The impact of HIV/AIDS on household income and livelihood, especially in already poor households, is devastating (NelsonMandela/HSRC, 2005: 111). Once again, women are the worst affected, as the stories of the women in this study show. It is with this in mind that I attempt to show the 'hurts and cries' behind the statistics. This is done through the life stories of the six women included in this research project. The biographical focus is spurred on by the thinking that the experience of suffering and the "texture of dire affliction" are not effectively conveyed by statistics or graphics, but can only be understood in the "gritty details of biography" (Farmer, 1997: 262). Emotional consequences of HIV/AIDS, which have different generational effects, are also explored. For example, I look at the strain of care-giving, financial difficulties, personal health problems, uncertainty and fear for the future, experienced by grandmothers. I also explore the feelings attached to living with a chronic illness, specifically AIDS and the stigma attached to it.

The central aim of this thesis, therefore, is to explore the practical everyday impact of the triple effects of gender, poverty and HIV/AIDS on the women in this study. The goal is to provide some insight into the lived experience and the forms of consciousness that the women express in their own interpretations of their life stories. For this goal, I share Chuengsatiansup's (2001) sentiments in his study *Marginality, suffering, and community: the politics of collective experience and empowerment in Thailand,* in which he acknowledges the work of scholars in bringing the social origins of suffering to the fore. He, however, points out the social scientists' failure in critically looking at "how the lived experience of suffering can attain a collective dimension and therefore be politically significant in forging politics of collective empowerment" (Chuengsatiansup, 2001: 32). I am of the opinion that the intergenerational interviews in this study offer a collective voice for the women in the two households, and if anything, empower them in interrogating their biographies. The larger story in which these women's biographies are embedded is the chronic poverty among Blacks inherited from the impoverishing South African colonial/apartheid history. In the following sections, I briefly discuss chronic poverty as it is contextualised within the South African past.

1.2 Chronic poverty and HIV/AIDS

The phenomenon of chronic poverty, according to the Chronic Poverty Research Centre (CPRC, 2004-5: 3) report, is a household's inability or lack of opportunity to better its circumstances from generation to generation. It is when people remain poor for much or all of their lives and are unable to sustain themselves through difficult times. The following Ugandan saying articulates well the manner in which this type of poverty is easily passed on:

> Some poverty passes from one generation to another as if the offspring sucks it from the mother's breast.
>
> Group of disabled Ugandan women in CPRC, 2004-05: 3

This observation is echoed in May's (1998) study *Experience and perception of poverty in South Africa*, in which he concludes that being born in a poverty-stricken household, or marrying into such a household, is a key long term trend for chronic poverty (May, 1998: 35). In addition, people living in these conditions die from preventable diseases and are extremely vulnerable to epidemics (CPRC, 2004-05: 3). This type of poverty exacerbates the impact of episodic calamities, such as the HIV/AIDS pandemic (Kleinman, Das & Lock, 1997: xx). Furthermore, people in chronic poverty face layers of social discrimination. For example, in South Africa, as is the case in most developing countries, a common scenario

> involves a coincidence of poor health, meagre education, and fractured families, on the one side, with skewed resource distribution, inadequate infrastructure, and scarce employment opportunities, on the other side. The combination is more than sufficient to trap many people in poverty, i.e. to make them chronically poor.
>
> Aliber, 2001: 2

As noted earlier, women are hard hit by chronic poverty and its consequences. For example, Steinberg *et al.*'s (2002) study found that three-quarters of the 771 households surveyed on the impact of AIDS, were female-headed and mostly elderly. These researchers, as other studies have shown, noted the devastating impact of HIV on already impoverished households. According to the authors, as bleak as the findings of this survey are, the households are relatively better off than other poor families who do not receive any help from NGOs. All participating households in this survey had contact with NGOs providing support to HIV-affected families. A major concern that Steinberg *et al.*'s (2002) study highlights is that in chronically poor households, HIV/AIDS is the tipping point from poverty to destitution. As noted above, poverty is an all-encompassing intergenerational phenomenon, which is usually passed on from one generation to the next. It is for this reason that a vast number of chronically poor women in Sub-Sahara

Africa see poverty as their prime concern above all others, including the risk or reality of HIV (UNAIDS, 2004: 15-16).

The above concern is noted by most researchers on AIDS. They have also found that those who are already economically and politically marginalized and oppressed suffer the most. As an elderly traditional healer in Mozambique declares: “when you have somebody sick in the house, poverty has already entered” (Breslin, 2003: 12). This impact on the poor demonstrates the capacity of HIV to exploit the fault lines of an already economically divided society, such as South Africa. The following discussion provides a brief socio-economic and socio-political historical context for the three generations of women in this study. The purpose of reviewing the apartheid/colonial history is not to suggest that poor black South African women are forever shackled to the past, the intention is to demonstrate the intricate relationship between apartheid/colonialism and the six women’s chronic poverty.

1.2.1 The South African situation

Many commentators acknowledge that poverty is the most serious challenge facing the South African post-apartheid rainbow nation (see Budlender, 1999; Harker, 1994; Ramphele, 2002). Budlender attributes endemic chronic poverty in South Africa to the unusual situation of “extreme levels of inequality” (1999: 1). She explains:

> Although South Africa is rated as a middle-income country, such ratings are typically based on aggregate value such as average per capita income. This average conceals the fact that a very large number of people are extremely poor while a much smaller number are extremely wealthy.

In South Africa, the life stories of the economically marginalised are intimately imbedded in its history. In addition, the “historical circumstances have shaped the present configuration of poverty and opportunities along racial lines” (Aliber, 2001: 5). It is widely acknowledged that the most significant factor distinguishing South Africa from other African countries is its experience of apartheid. The segregationist policies of the apartheid era worsened the living conditions of blacks, which had been in decline since colonial rule (Ross, 1999: 54-113). The life stories of the women in this study show that the consequences of colonialism/apartheid continue to be felt by most black South Africans. Archbishop Desmond Tutu sums up this reality:

> Apartheid has left a ghastly legacy. There is a horrendous housing shortage and high unemployment; health care is inaccessible and not easily affordable by the majority; Bantu education has left us with a massive educational crisis; there is gross mal-distribution of wealth and an inequitable sharing of the resources with which South Africa is so richly endowed. Some 20 per cent of the population owns 87 per cent of the land. Then there is the hurt and anguish of those who were forcibly removed from their homes, nearly 4 million people.
>
> Tutu in Harker, 1994: 208

One of the devastating social consequences of apartheid is ill-health for the majority of blacks. This is due to living a deprived life, in overcrowded homes, with little or no sustainable income. During apartheid, health standards among whites resembled those in developed countries, whereas among blacks it resembled those in developing countries (Welsh, 1994 in Harker, 1994: 43). This situation, as is the case with other social imbalances, continues to be the case 12 years into the New South Africa. This is illustrated in the *NelsonMandela/HSRC study of HIV/AIDS: South African national HIV prevalence, behavioural risks and mass media – household survey 2002* report. The researchers found that HIV/AIDS has the highest burden among black South Africans and that 80% of them utilise the under-funded public health services. In contrast, the well-resourced private health service is utilised by 20% of the predominantly white middle class and wealthy South Africans (NelsonMandela/HSRC, 2005: 133-134). Other studies on health issues also show a positive correlation between poverty and poor health. Poverty is a major factor in the transmission of infectious and contagious diseases (e.g. AIDS and Tuberculosis), as it is for other forms of social suffering (CPRC, 2004-5; Kleinman, Das & Lock, 1997). The stories of the women in this study will show how poverty exacerbates the suffering inherent in the experience of AIDS or other chronic illness.

1.2.2 Black women in colonial South Africa

It is well documented that black women suffered a specific form of marginalisation in colonial and apartheid South Africa (e.g. Barrett *et al*., 1985; Bozzoli, 1991; Ross, 1999). They were not recruited in the mining or the farming sectors. In the latter, they were only employed as seasonal workers with worse working conditions than black men. This work-related gender discrimination is exemplified by one grandmother's experience of farm work in this study discussed later (see 6.4). The main form of employment for black women was domestic work. In their book *South African women on the move*, Barrett *et al.* (1985) present the lived experiences of black women in apartheid South Africa, which reflects the desperation felt by many black South Africans, particularly women, because of pass laws. One such story is of a woman born in 1930 in a township near Frankfort in the then Orange Free State province. She moved to a township in Johannesburg in 1946 and worked as a domestic servant for various white people. In 1964 she applied for a pass, as she was selling beer and needed to 'legalise' her stay in the township. She was imprisoned for six months for selling beer illegally. She was once married and had three children, but her husband deserted her in 1982. At the time of Barrett *et al.*'s study in 1984, this woman was in trouble because neither her residence nor her employment had ever been reflected in the reference book (pass book). If caught she would have been deported to Frankfort, her place of birth to which she had not returned since 1946. These researchers note how this woman's story was better than the women in rural areas. Her rural contemporaries were excluded by influx control and pass laws from finding work in urban areas or from living with their husbands. If and when the rural women succeeded in going to the urban areas, they lived in constant fear of being arrested. They took extra low-paying domestic work because they could not challenge low wages or bad working conditions (Barrett *et al.*, 1985: 7-15).

In addition, Barrett *et al.* (1985) point out how domestic work and housework isolated women from each other, and locked them into a daily experience of solitary suffering. Domestic work was tedious and tiring, and involved long working hours. If the women were 'live-in' workers, then they may have been always on call (ibid.: 31). Doing domestic work separated them from their men, and as wives they were dominated and often maltreated by their husbands. This is illustrated in the following common observation of black women's domestic life in the Barrett study:

> For most women life outside of work is a grind of household responsibility and very often violence and degradation. Many have opted to live as 'singles', and often resent men. Other women feel that they have no choice but to accept the situation. Maureen Sehlokwa has left her husband after many batterings. Her finger is bent, and her husband cracked her ribs … Many women receive no economic support from their husbands or boyfriends. These men may be unemployed, or live in another town and may not send remittances, or take responsibility for their women and children.
>
> Barrett *et al.*, 1985: 136, 139

Other researchers have noted how the 'singles' may appear to be free of everyday male authority and violence in their household, but that economic dependence on their absent husbands and partners results in emotional and physical (lack of adequate food) suffering. These studies on female-headed households demonstrate that these women are the poorest of the poor and have limited access to land, animals and money (Bozzoli, 1991; Fortmann, 1984; Sachs, 1996). This discussion shows that black women were simultaneously dominated by the colonial/apartheid structures and the men in their own households. This dual domination continues in post-apartheid South Africa.

1.2.3 Black women in the new South Africa

Beyond the legacy of apartheid as articulated by Desmond Tutu above, black women living in poverty experience patriarchal domination more than other women in South Africa. Patriarchy, as feminists argue, is at the root of "the pervasiveness and interconnectedness of different aspects of women's subordination" (Walby, 1990: 2), and can be used to explain the different forms of gender inequality. It is seen as a system of social structures and practices in which men dominate, oppress and exploit women. As suggested by Walby (1990: 20), it exists as a system of social relations in theory, and in colonial South Africa this includes the emergence of capitalism and racism. In practical terms, argues Walby (1990), patriarchy is composed of six structures which restrict women and help to maintain male domination:

1. **The patriarchal mode of production:** Patriarchal production relations in the household mean an expropriation of the women's domestic labour by their husbands and partners. The family is conventionally considered to be central to women's lives and to the determination of gender inequality. As a site of production relations, its significance, for feminists, is that men oppress women, in that men benefit from women's domestic labour (Walby, 1990: 61-89).
2. **The patriarchal relations in paid work:** The second patriarchal structure within the economic level is that of patriarchal relations within paid work. A complex of forms of patriarchal closure within waged labour exclude women from better forms of work and segregate them into the worse jobs which are deemed to be less skilled (ibid.: 25-59).
3. **The patriarchal relations in the state:** The state is patriarchal as well as being capitalist and racist. While being a site of struggle and not a monolithic entity, the state has a systemic bias towards patriarchal interests in its policies and actions. Men monopolise positions of political power (ibid.: 150-172).
4. **Male violence:** Male violence constitutes a further structure, despite its apparently individualistic and diverse form. Male violence is systematically condoned and legitimated by the state's refusal to intervene against it except in exceptional instances, though the practices of rape, wife beating, sexual harassment, etc. are too decentralised in their practice to be part of the state itself (ibid.: 128-149).
5. **The patriarchal relations in sexuality:** Patriarchal relations in sexuality constitute a fifth structure. Compulsory heterosexuality and sexual double standards are two of the key forms of this structure (ibid.: 109-127).
6. **The patriarchal relations in cultural institutions:** Patriarchal cultural institutions complete the array of structures. These are significant for the generation of a variety of gender-differentiated forms of subjectivity. This structure is composed of a set of institutions which create the representation of women within a patriarchal gaze in a variety of arenas, such as religious, education and the media. Ideas about masculinity and femininity are to be found in all areas of our social relations; they are part of the actions which go to make

up the patriarchal structures. How is gender represented, culturally (ibid.: 90-108)? *In the case of rural black South African women, this includes traditional customs such as lobola (bride price), where a woman is seen as the man's 'property'.*

The above structures, as other feminists have pointed out, are interlinked and have causal effects on each other (Bartky, 1990; Bryson, 1992). Feminist theory is fundamentally about explaining these varied forms of women's oppression. It seeks to understand why women are oppressed (Stanley & Wise, 1993: 45-48). In this study I make use of these feminist ideas for two reasons. First, black women in present day South Africa continue to experience male domination, both at work and at home. The flurry of gender activities and the emergence of gender institutions in post-apartheid South Africa bear testimony to this claim (POWA – People Opposing Women's Abuse, Commission for Gender Equality, etc.). Second, the phenomenon of AIDS, as earlier noted, follows the unequal gender dynamics in society, especially among the poor.

1.2.4 Family disruptions

Another devastating consequence of colonialism and apartheid is the disruption and destruction of black South African family structures through the migrant labour system. The key contributing factor was the advent of the mining industry in the mid to late 19th century. With it came migrant labour and the 'influx control' policies, which limited the mobility of Africans to 'homelands'. Several inhumane acts (e.g. Pass laws, 1913 Native Land Act, 1950 Group Areas Act, 1954 Bantu Urban Areas Act and 1970 Black Homeland Citizenship Act) were passed to force men to work in the emerging mining industry and related sectors, including agriculture. The Native Land Act formalised the distinction between the African Reserves and white farming areas, prohibiting Africans from acquiring, owning, and renting land in the latter. This effectively limited their economic options, and compelled men to seek work on the mines or on white farms. This Act and others were calculated to break up the autonomy of African producers by effectively eliminating their access to land in the prohibited areas and squeezing them into reserves as potential, hidden, wage labourers (Hendricks, 1990: 23-24, 148; Ross, 1999: 54-113).

As most commentators have noted, past family destruction is at the heart of many social ills rampant in black communities, even in post-apartheid South Africa. Ramphele's (2002) study, *Steering by the stars: being young in South Africa* depicts the consequences of disrupted families on the youth in poor urban communities. Her study was conducted in New Crossroads, a black township in Cape Town, South Africa. Through the stories of teenage children, she makes the reader understand how post-apartheid South Africa is being experienced at the grassroots level by those growing up in poverty. The stories show the struggles waged by young people of New Crossroads who are not yet benefiting from the fruits of the New South Africa. Theirs is a life experience bearing all the scars of the legacy of the past – inadequate social amenities; overcrowded homes; the daily grind of poverty that undermines the dignity of ordinary citizens and makes for stressful family relationships; underperforming schools that provide little hope for a better future for them; violent homes, schools and streets that add to the general insecurity in New Crossroads.

The stories of the third generation of women, the granddaughters, in the present study echo the stories of the youth in Ramphele's (2002) study. As I will show in Chapters 5 and 6, HIV/AIDS simply compounds the suffering experienced as a result of poverty and its ensuing social effects as it is contextualised in the South African colonial/apartheid history.

1.3 An overview of the thesis

The preceding discussion provides a brief background context for the women's stories. The two themes of poverty and gender inequality will continue to be fleshed out in the thesis. Chapter 2 looks at the philosophical and theoretical assumptions underlying phenomenology, a theoretical foundation for this study. A key assumption in phenomenology is that human beings continuously make sense and meaning of their lifeworlds in everyday taken-for-granted experiences. Included in this discussion is the phenomenon of emotion from a constructionist and feminist perspective. The inclusion of these two approaches, especially feminist ideas, serves to highlight the taken-for-granted oppression in everyday experiences, such as patriarchy. This also deals with a weakness inherent in phenomenology, namely a lack of concern for the role that social structures play in shaping and informing an individual's subjective consciousness and experience. This is followed by a review of empirical studies on lived emotions as experienced by those living with a chronic illness and as experienced by those caring for them. The emotions of anger, sadness, and fear are looked at. Discussed at length is the emotion of shame as it is experienced by individuals living with AIDS, an illness with stigma attached.

Chapter 3 continues with the theme of negative emotions attached to living with a chronic illness. Using the concepts of 'biographical disruption' (Bury, 1982) and 'loss of self' (Charmaz, 1983), the discussion shows how a chronic illness disrupts the underlying ontological assumptions individuals hold about their lifeworld. This includes the disruption in relationships with significant others. Following this is a review of studies on the coping mechanisms that individuals employ in dealing with the disrupting effects of a chronic illness. The concept of 'narrative reconstruction' (Williams, 1984) is used to illustrate how a disrupted biography or lost self due to an illness is re-established through different forms of story telling. These stories attempt to give meaning and explanations of the illness experience. I then discuss practical coping strategies that the chronically ill utilise. These include seeking help from family members, from public health services and government social grants, from NGOs, and from religious institutions.

In Chapter 4, the methodology, research methods and techniques used in this study are discussed and described. This is underpinned by the phenomenological considerations covered in Chapter 2. The focus is on how the two sets of three generations of women make sense of their lived experiences in relation to each other. The aim in this study is to obtain rich descriptions of the women's life stories through in-depth interviews. The interview transcripts from this study are used as illustrations in the discussion of the on-going qualitative methodology issues and limitations (Gubrium &

Holstein, 1997: 3-16). How are biographical narratives co-constructed between the women and the researchers (myself and the translators)? Who has ‘control’ of which and what stories get told? I then reflect on my role as a researcher.

In Chapters 5 and 6, I present the interpreted stories of the women, starting with a brief biographical account of each of the six women. The abridged biographies enable the reader to better understand and appreciate the interpreted narratives of the women as discussed in these two chapters. The selection of themes was guided by the study topic, the reviewed literature and by the women. Being guided by the women is in line with the flexible nature of qualitative research as discussed in Chapter 4. In one household this involved the unintended inclusion of two grandsons in the study as they have an impact on the grandmother, mother and granddaughter’s stories. This is especially the case with the story on the management of the grandmother’s old age social grant. Chapter 5 focuses on poverty and AIDS narratives, while Chapter 6 centres on patriarchy as it is experienced by the six women.

Chapter 7 provides a reflection on and conclusion to the study.

CHAPTER 2
PHENOMENOLOGY, FEMINISM AND EMOTIONS: A LITERATURE REVIEW

2.1 Introduction

A key assumption in phenomenology is that people seek to create meaning of their lifeworld by drawing on commonly held ‘stocks of knowledge’ (Alfred Schütz in Craib, 1984: 86). This knowledge primarily involves our consciousness of the world around us and the meaning we make of it. Thus, phenomenology is about understanding and interpreting the meaning of phenomena or things, instead of explaining how they came into existence (Haralambos, Holborn & Heald, 2000: 1050). In this chapter I look at the philosophical and theoretical assumptions underlying this form of social inquiry.

Included is a discussion on emotions from a phenomenological, constructionist and feminist perspective. The aim of the literature review on emotions is to highlight how feelings overshadow our rational selves and disrupt our self-concepts under conditions of chronic illness. In addition, it serves to demonstrate the emotional effects on significant others, who are caring for and living with a chronically ill individual. As the stories of the women in this study show, emotional anguish is not confined to illness experiences. It is ubiquitous when compounded with chronic poverty. For the purposes of this study, theoretical literature on emotions underpins the interpretation of the women’s life stories. It is not my intention to focus on emotions as a specific field of study. The references to emotions merely serve to enhance our understanding of these six women’s lived experiences.

In the final section, I review literature on empirical studies of the emotional lives of individuals living with a chronic illness such as AIDS. This disease is psychosocially seen as “a chronic illness with a long term, incapacitating, terminal and stigmatizing character” (D’Cruz, 2004: 413). It has a devastating impact, both emotional and physical, on the infected individual and her/his family members. As mentioned in the previous chapter, this is especially the case for those living in poverty. Women in poor households are particularly hard hit as they are normally more burdened with care responsibilities for family members with AIDS. This is in addition to the various household chores that they already perform (UNAIDS/UNFPA/UNIFEM, 2004: 31).

2.2 A look at the phenomenology of the common sense world

Phenomenology, like other interpretive perspectives, rejects the notion that society has a clear structure that directs human action. Instead, in this tradition it is suggested that the world we live in and human action are constituted and given meaning in our consciousness. Philosopher Edmund Husserl (1859-1938), a founding father of phenomenology, developed a critique of positivism and scientific knowledge by developing "a philosophy that goes to the roots of our knowledge and experience" (Craib, 1984: 83). He argued that social inquiry and scientism was disconnected from the common sense world and activities in which it is rooted. It is for this reason that he suggested a method aimed at studying human phenomena without considering questions of their causes, their objective reality, or even their appearances. This, he argued would restore the connection lost in positivist pursuits (ibid.). Thus, for him and his followers, the aim is to study how human phenomena are experienced in consciousness, and how individuals are engaged in the process of making sense of their everyday lifeworld. The underlying difference between the social and physical sciences is that in the former one is dealing with conscious objects that are themselves interpreting the social world that we, as scientists, also wish to interpret.

Alfred Schütz (1899-1959), following Edmund Husserl's philosophizing, developed many of the key ideas of phenomenology. A central assertion of his is that human beings construct meaning out of the everyday taken-for-granted experiences through a process of *typification*. This is a process of identifying, classifying, comparing and making sense of the social phenomena and the non-social environment (Babbie & Mouton, 2001: 28-30; Berger & Luckmann, 1967: 45-8; Craib, 1984: 85). Implicit in this simple, yet profound, observation is the notion of interpretation of these multiple realities encountered in everyday life. Individuals are continuously involved in the enterprise of interpreting "an intersubjective world which all human beings share" (Babbie & Mouton, 2001: 28). Therefore the job of a phenomenologist is to employ *second-order typification*s to understand and describe the interpreted meanings of the particular phenomenon s/he is studying (Schütz, 1972 in Benton & Craib, 2001: 84). These ideas also resonate with Max Weber's (1864-1920) concept of 'ideal types' and his emphasis on subjective understanding or interpretation (Verstehen) of human action or experience.

Berger and Luckmann's (1967) ideas in their book, *The social construction of reality*, build on Schütz's work. However, they go beyond phenomenological analysis of the reality of everyday life by integrating this with more structural and materialistic explanations. They nonetheless also see phenomenology as an appropriate method to understand the foundations of knowledge in everyday life. A central argument, as demonstrated in the title of their book, is that "reality is socially constructed and that the sociology of knowledge must analyse the process in which this occurs" (Berger & Luckmann, 1967: 13). For them, this means an inclusion of Karl Marx's concepts of *ideology* and *false consciousness* in the analysis of social reality. What interests them is Marx's idea that human consciousness emerges in human activity, precisely 'labour' (Berger & Luckmann, 1967: 18). It is for this reason that I include feminist phenomenology of oppression (see 2.2.3), because women's consciousness is, to a large extent, shaped and informed by domestic labour.

Ontologically, like Schütz before them, Berger and Luckmann (1967: 35) see the world and social reality as consisting of multiple realities. The primary reality for them is "the reality of everyday life" which is perceived as "an ordered reality" (ibid.). This reality is organised around the *here* of one's body and the *now* of one's present (ibid.). They explain:

> Closest to me is the zone of my everyday life that is directly accessible to my bodily manipulation … In this world of working, my consciousness is dominated by pragmatic motive, that is, my attention to this world is mainly determined by what I am doing, have done or plan to do in it.
>
> Berger and Luckmann, 1967: 37

Thus to know this reality, one needs to identify the subjective and intersubjective consciousness involved in these mundane daily experiences. In effect, the taken-for-granted everyday life presents itself to the phenomenologist “as the reality *par excellence*” (Berger & Luckmann, 1967: 35). This is because the ‘meaning contexts’ of everyday experiences build into ‘stocks of knowledge’, which in turn constitute an individual’s lifeworld (Alfred Schütz in Craib, 1984: 86). The methodological focus is on understanding the subjective meaning of everyday life as “it is manifested in an intersubjective consciousness” (Johnson, 1981: 60). Great emphasis is placed on the social processes which point to “a social reality created and experienced as objectively factual in individuals’ subjective consciousness” (ibid.). In this study, focus is placed on the intergenerational familial experiences and how these inform the women’s objective reality, as discussed in Chapters 5 and 6. Berger and Luckmann (1967: 37) expand on this point:

> The reality of everyday life presents itself to me as an intersubjective world, a world that I share with others. This inter-subjectivity sharply differentiates everyday life from other realities of which I am conscious … I cannot exist in everyday life without continually interacting and communicating with others. I know that my natural attitude to this world corresponds to the natural attitude of others, that they also comprehend the objectifications by which this world is ordered, that they organise this world around the ‘here and now’ of their being in it and have projects for working in it.

In this perspective, it is suggested that the most important thing you can know about the individual is how s/he privately sees, interprets, feels, or understands the world (Gergen & Gergen, 2003: 60), how s/he classifies and makes sense of the world around her/him. As my study shows, phenomenological research seeks to explore lived experience directly and aims to understand and illuminate its meanings from the inside – the subjective perception of the study participants. In the following two sections, I briefly discuss the phenomenon of emotion, grounded in the preceding phenomenological considerations. A review of the phenomenon of emotion became necessary during the interviews with the six women. Their stories were emotively narrated, especially the principal participant (see 5.2), who explicitly described herself as ‘angry’.

2.2.1 Phenomenology of emotion and selfhood

In phenomenology, the experience of emotion is seen as being "integral to our selfhood and the ways in which we access and deal with others" (Lupton, 1998: 21). The key to emotional experience is an individual's lived experience and judgement built up from an individual's membership of and experiences in a particular social milieu. An individual's range of feelings – distress, anxiety, boredom, alienation, love, sympathy, etc. – are all "manifestations of the personal and private apprehensions the individual has made of the world" (Finkelstein 1980 in Lupton, 1998: 21). A phenomenological interpretation of emotion would "uncover layers of experience and the different structures of meaning involved" (Berger & Luckmann, 1967: 34). This includes emotions attached to living with a serious illness, such as fear and anger, discussed below (2.3).

The phenomenological approach to emotion and selfhood may be summed up in Norman Denzin's suggestion that "emotions are nothing less than central to the ontology of human existence" (1984: 1). According to him, emotions lie at the core of the self and give rise to ways of being in the world. He suggests that people are, indeed, their emotions. For him then, "to understand who a person is, it is necessary to understand that individual's emotion" (Denzin, 1984: 1). In his book *On understanding emotion,* his key research question is how emotion, as an embodied "form of consciousness, is lived, experienced, articulated and felt" (Denzin, 1984: 1). His essential proposal in this work is that emotions are intersubjective, that is, they emerge from the process of meaningful exchanges between individuals. Further, he proposes that individuals interpret emotions to be located in understandings of selfhood. An individual's experience of emotion, for him, involves the implicit or imagined presence of others. This means that all experiences of being emotional become "situational, reflective and relational" (Denzin, 1984: 3). Similarly, "lived emotion permeates an individual's stream of consciousness … through the lived phenomenological body, to the world of intentional value feelings, self-feelings, and the feelings of a moral person" (Denzin, 1984: 106, 129). Denzin concludes that lived emotion is an intersubjective phenomenon, which joins two or more individuals into a shared emotional field of experience (1984: 130).

In a similar vein, philosopher Peter Goldie suggests that everyday understanding of emotions such as anger or sadness shows them to be complex, episodic, dynamic, and structured (2002: 12-13). For Goldie, emotions are complex because they typically involve many different elements. This includes episodes of emotional experience, including perceptions, thoughts, a range of feelings, and bodily changes of various kinds. He sees emotions as being episodic and dynamic because over time, the elements can be fleeting, come and go, increase and decrease, depending on various factors. For example, living with a chronic illness may increase feelings of anger towards self or/and others, due to the loss of control of bodily and social functions. Goldie further explains that emotions are structured because they "constitute part of a narrative – roughly, an unfolding sequence of actions and events, thoughts and feelings – in which the emotion itself is embedded" (2002: 13).

The role of emotions in the emergence of narrative is central to my study. This significance is based on the fact that emotions influence memory and the interpretation of everyday life experiences. In addition, emotions make reality subjective. Commentators and researchers on emotions argue that our primary awareness of the world consists of our emotional responses, not affect-less knowledge (Denzin, 1984; Goldie, 2002; Hardcastle, 2003; Lupton, 1998; Lutz, 1986; Shott, 1979). They contend that rationality includes the emotional appraisal of the world. They also observe that our emotional reactions drive our personal life narratives. For them, emotional ties to family and friends are what determine what gets into our narratives of self. Thus, the centrality of emotions in our lives means that the experiences and things that we have labelled as significant (either good or bad) make it into our stories. In this view, then, as Hardcastle (2003: 354) suggests:

> We use our idiosyncratic desires to guide our existence, and as these remain constant over time they allow us to hypothesise a common core that powers our behaviour. Our very 'centre of narrative gravity' depends on there being something that remains relatively unchanged through significant chunks of our lifespan. Our emotional reactions are just that thing. Because we react similarly to similar inputs, we gain a sense of unity across our thoughts, actions and reactions. This unity is then reflected in our narrative stories of self.

The emotionally informed narrative stories of the self include the ‘disrupted biographies’ during a serious or chronic illness (Bury, 1982: 167-82). The saliency of emotions during an illness highlights the subjective and intersubjective disruption of everyday life and the forms of knowledge underpinning it (Pierret, 2003: 7). Listening to emotional narratives and how illness experiences affect individual lives and relationships, give rise to what Arthur Kleinman terms “empathic witnessing of the existential experience of suffering” (1988: 10). This means identification with the suffering either through the knowledge gained from prior personal experience or that of significant others. In other words, it is drawing on Alfred Schütz’s ‘stock of knowledge’, that is, subjective knowledge embodied in a body of common sense illness knowledge.

2.2.2 A social constructionist perspective on emotions

The above ideas resonate with the social constructionist perspective. Like phenomenology, this perspective’s basic assumption is that “the reality which human beings inhabit is socially constructed and that reality includes biology, which is still culturally constituted and socially transformed” (Turner, 1984: 209). From a constructionist standpoint, this means that most experiences that we attribute to human emotional nature are socially constructed (Gordon, 1981: 562-592). For constructionists, emotions emerge and are shaped through the symbolic interaction of individuals within specific socio-cultural contexts (Shott 1979: 1317-1334). Symbolic interaction starts in primary socialisation, which goes beyond cognitive learning, and “takes place under circumstances that are highly charged emotionally” (Berger & Luckmann, 1967: 151). This focus on the socio-cultural nature of emotions suggests that certain emotions can only exist in the reciprocal exchanges found in social relationships (Harré, 2003: 147).

Like phenomenology, this perspective also views emotion as an intersubjective rather than individual phenomenon, constituted in the relations between people (Lupton, 1998: 16). A general focus for social constructionists, therefore, is to demonstrate how emotional experiences are socio-culturally constituted or influenced. The use of social construction ideas in this study serves to highlight how chronic poverty, HIV/AIDS and gender shape the participant’s emotional selves. Indeed, it is the socio-cultural contexts, such as poverty, that structure how emotions are experienced and expressed (Thoits, 1989: 323-328).

2.2.3 Feminism and emotions

In this section, the phenomenological and constructionist ideas are juxtaposed with the feminist standpoint on patriarchy. This juxtaposition is necessary in this study, as it provides a framework that underpins the interpretation of the patriarchal context in the women's life stories. This attempts to supplement what is often regarded as a shortcoming in phenomenology, namely the lack of concern or interest in the role played by social structures, institutions, and power relations in the individual's lifeworld. Feminists argue that the phenomenology of oppression permeates not only social relations, but informs subjective concepts of emotional selves for women (Bartky, 1990: 83-98). Using the example of the emotion of shame, feminist philosopher Sandra Bartky shows how patriarchal domination structures women's lived emotional experiences. She acknowledges that men and women have the same fundamental emotional capacities. Shame, for example, is not gender-specific. However, she argues that women are more prone to experience shame and "the feeling itself has a different meaning in relation to their total psychic situation and general social location than has a similar emotion when experienced by men" (Bartky, 1990: 84). The difference for Bartky is that men's shame "may be intelligible only in light of the presupposition of male power, while in women shame may well be a mark and token of powerlessness" (ibid.). She concludes that:

> Women typically are more shame-prone than men, that shame is not so much a particular feeling or emotion (though it involves specific feelings and emotions) as pervasive affective attunement to the social environment, that women's shame is more than merely affect of subordination but, within the larger universe of patriarchal social relations, a profound mode of disclosure both of self and situation … Shame, then, involves the distressed apprehension of oneself as a lesser creature.
>
> Bartky, 1990: 85-86

The focus for feminists, then, is on understanding "why women tolerate social relations which subordinate their interests to those of men and the mechanisms whereby women and men adopt particular discursive positions as representative of their interests" (Weedon, 1987: 12). This means that feminists place great emphasis on micro politics and on subjectivity, difference and everyday life. For them, the concept of emotion has an ideological function. This means that "…it exists in a system of power relations and plays a role in maintaining it" (Lutz, 2003: 40). Kate Millet in her book *Sexual politics* (cited in Gamble, 2001: 36-37) asserts that patriarchal ideology is internalised by women. For Millet, patriarchy is "a political institution, and sex a status with political implications" (ibid: 36). She, like other radical feminists, sees patriarchy as the primary form of human oppression**,** which is maintained mainly through ideological control. This includes the women's "psychological and emotional facet of existence" (ibid). The development of a passive temperament and a sense of inferiority by women are thus pinned down to patriarchal ideology. For Millet and others, sexist language reinforces universal male domination, and abets women in taking men's domination over them for granted. The sexist language is seen as a kind of social mirror, which reflects the organisation and dynamics of society and the oppressed status of women (ibid.).

Feminists, therefore, are more interested in the discursive construction of emotional experience and how individuals participate in this process by adopting or resisting dominant discourses, and the constitutive role played by language (Lupton, 1998: 24-27, 38). For them, discourses do not simply reflect or describe reality, social relationships, social institutions and practices. Instead, discourses play a central role in constructing social reality (Weedon, 1987: 21-27). This means that "discourse is a practice not just of representing the world, but of signifying the world, constituting and constructing the world in meaning" (Fairclough, 1992 in Lupton, 1998: 64). Therefore, when one is speaking about emotions, the words used have meanings that go beyond the label attached to the emotion. Feminists point to stereotypical ways in which different emotions are labelled and experienced. Anger, for example, has different meanings attached to it when it is referred to women and men. A woman's anger may be viewed as a sign of neurosis, whereas a man's emotional state of anger may be construed as a rational reaction to annoying external factors (Lutz, 1986: 299). The gender-specific meanings attached to an emotion such as anger, show how:

> experience has no inherent essential meaning. It may be given meaning in language through a range of discursive systems of meaning, which are often contradictory and constitute conflicting versions of social reality, which in turn serve conflicting interests. This range of discourses and their material supports in social institutions and practices is integral to the maintenance and contestation of forms of social power, since social reality has no meaning except in language.
>
> Weedon, 1987: 34

This view that women are more emotional than men serves as justification for institutional and domestic (familial) subjugation of women. Consequently, as Lutz (1986: 300) argues: “when women are said to be emotional, their inferiority is also generally asserted given the general cultural devaluation of the concept of emotion”.

The discussion so far has centred on the pervasive nature of emotion in everyday life experiences, and how it informs and shapes the self. Like Lupton (1998: 38), I am also interested in interpreting “the lived experience and the social relational dimension of emotion”, including the roles played by poverty, patriarchy and HIV/AIDS in the women’s emotional experiences.

2.3 Emotions associated with chronic illness

The discussion now focuses primarily on lived emotions, as experienced by individuals living with a chronic illness and as experienced by those caring for them. As discussed above, emotional experiences are, to a large extent, structured and influenced by socio-cultural and historical contexts, such as patriarchy and apartheid. Internalisation of these external contexts shape and inform the subjective feelings and expression of emotions such as sadness, anger, joy and fear. Research findings show that the predominant emotions for individuals living with a serious illness are usually morbid and gloomy. For example, Ohman, Soderberg & Lundman (2003) in their study, *Hovering between suffering and enduring: the meaning of living with serious chronic illness,* note three major themes on despondent feelings from the interpreted interview transcripts of five women and five men living with various chronic illnesses. First, the participants experienced the body as a hindrance. This theme was constructed from the participants who noted that their bodies were without strength, that their bodies were in pain and agony, and that they had lost independence. Second, participants felt socially isolated and marginalised. They felt like outsiders, they hovered between hope and despair, they had feelings of uneasiness and they feared death. The third theme is about the participant's struggle for normalcy. In this theme, participants tried to understand and looked for explanations/meaning of their illnesses. They tried to integrate the changes and live as they did before the illness (Ohman, Soderberg & Lundman, 2003: 531-536).

Despite the saliency of negative feelings, researchers have noted the way certain individuals see a serious illness as an opportunity for growth. Kleinman (1988:137) points out that "there are many persons with chronic disorders and even severe disabilities who live lives of exemplary courage *and hope*" (italics added). There is extensive literature showing the ability of individuals living with a chronic illness to "create an enhanced appreciation of life's basics" (Crossley, 2000: 89), and to find meaning in their illness (Ohman, Soderberg & Lundman, 2003). For example, a number of people living with HIV/AIDS make being HIV-positive meaningful by speaking about their experiences and educating others about the dangers of AIDS (Cardo, 1999: 130-131). However, in this study the focus is on the negative emotions associated with living with a chronic illness. This is a deliberate choice as the life-stories of the women in this study are dominated by adversity, and HIV/AIDS no doubt exacerbates the situation.

2.3.1 Anger

When one is diagnosed with a serious illness, anger is often a natural reaction to the news. This may happen instantly or it may take a while for the anger to be acknowledged. Nonetheless, individuals do recognise the anger attached to an illness. Significantly, researchers have found that this recognition helps in dealing with the 'disrupted-self' and is part of the mourning process of the healthy self (Bury, 1982: 168-170; Kleinman, 1988: 29). The mourning is usually initiated by angry questionings: "Why me? What have I done to deserve this? Why have I been singled out? Why? Why? Why?" (Dennison, 1996, in Crossley, 2000: 82). Studies show that individuals with a serious or chronic illness go through this mourning process, and that it comes at different times for each individual and at different levels at each stage of the illness (Crossley, 2000: 82). For example, David Karp (1996) in his book, *Speaking of sadness: depression, and the meanings of illness*, writes about the personal anger he feels towards himself and others for not being able to live normally because of his chronic depression. Talking about the frustration (a common form of anger) he felt at his inability to sleep, Karp writes:

> The loneliest moments of my life have been in the middle of the night while, as I imagined it, everybody else was sleeping … I felt angry toward those who were sleeping, especially my wife who was right there so visibly and easily doing what I couldn't and desperately needed to do. Whatever bad feelings I had were intensified in the middle of the night. It was as though the volume of my personal agony had been turned to a deafening pitch.
>
> Karp, 1996: 6

This example shows that anger is not simply directed at his wife, but at the loss of control to perform a daily routine function, namely sleep. This anger towards self resonates with the Western concept of the self, where an individual is perceived as an autonomous being, and in control of him/herself. In the Western world-view, self-discipline and autonomy are privileged (Lupton, 1998: 71) and as is shown in David Karp's example above, the inability to control bodily functions, such as sleep, can be a source of suffering and frustration. However, evidence from several studies on illness experiences from non-Western societies show that such anger is also directed towards the self. For example, a 34-year-old black South African male living with AIDS was initially angered at the probable 'disintegration' of his body as he progressed to full blown AIDS and the consequent inability to look after his children:

> My idea about AIDS was a person gets thin and thin with sores around his mouth and face and body. I didn't want to experience that. I thought of my children. My last born is two – I've got five children. I said that there is nothing I can do. I took a pen and wrote all the reasons why I should commit suicide.
>
> Pat, 34 years old (Cardo, 1999: 186)

Anger is also felt by those close to the person with an illness. A stigmatizing illness such as AIDS negatively affects family members of the HIV-positive individual.

For example, some children attending the ‘National Children’s Forum on HIV/AIDS’ in Cape Town, South Africa, spoke about the anger arising from the social consequence of living in a household where someone is HIV-positive. Lindiwe, 15 years old, noted that even though she was not HIV-positive herself, she is nevertheless referred to as HIV-positive because she stays with a brother who is HIV-positive. She said that this happens a lot at school, where some children think that she might infect them (Giese, 2002: 41). Another teenager in the same workshop explained the frustration associated with living in a household where there is an HIV-positive parent:

> Everybody talks about their parents. It is not nice because these children still love their parents even if they are HIV-positive, it does not mean that people should discuss their illness. How they get it is not important because it won’t make them HIV negative. People don’t want to accept and respect people with HIV/AIDS.
>
> Douglas, 17 years old (Giese, 2002: 41)

It is not only young children who feel the rage and anguish of living with HIV parents or relatives. Grandparents often experience these emotions as well. Studies show that parents of HIV-positive individuals experience anger and pain at the way this illness stigmatizes them too (Burt, 2003; WHO, 2002). Studies in Southern Africa show the anger and psychological pain felt by elderly women affected by AIDS. These women, mostly grandmothers, themselves in need of caring, experience anger at the twist of fate – having to care for a child dying of AIDS as well as becoming ‘mothers’ to their grandchildren (Baylies & Bujra, 2000; Breslin, 2003; Burt, 2003; WHO, 2002). This anger and anguish is illustrated in Burt’s (2003) study, *An exploration of the impact of AIDS-related losses and role changes on grandmothers.* The grandmothers expressed anger at having to bear the burden of caring for their ill children and taking on the mother role to their grandchildren. This frustration was compounded by the lack of support from extended family members. For example, a 60-year-old grandmother described her feelings regarding the isolation she feels as a care-giver:

> I used to hold a grudge towards my family when I was caring for my child. I used to think to myself where is the rest of the family? Why can’t they come forward and help me? I used to feel angry, asking myself – why am I alone with this?
>
> Burt, 2003: 36

2.3.2 Sadness

As with anger, sadness is a human emotion that is often felt at the onset of a serious illness or when one is living with a chronic illness. As illustrated in an earlier quote on inability to sleep, loss of control over bodily and social functions causes anger as well as feelings of deep sadness. In his earlier cited book, David Karp gives an insightful reflection of his depression, including personal accounts of 50 study participants' experiences of living with chronic depression. The central theme in this study is the emotion of sadness. For Karp, sadness is synonymous with clinical depression, whose signs are:

- Inability to experience pleasure in previously pleasurable activities
- Sleep disturbances – difficulty sleeping, early morning waking and unable to get back to sleep, extended sleeping with fatigue even after a long sleep
- Changes in eating habits – usually decrease in appetite and food losing its taste, but sometimes overeating without increase in appetite
- Feelings of guilt, helplessness and/or hopelessness
- Increase in self-critical thoughts
- Thoughts of suicide
- Increased isolation from friends
- Poor self-esteem

DSM-IV, APA, 2000 in Nolen-Hoeksema, 2001: 248

As is the case with anger, sad feelings are also experienced by those directly caring and living with an individual who has a serious illness (Breslin, 2003; Burt, 2003; D'Cruz, 2004; Karp, 1996; Kleinman, 1988). It is distressing and saddening to see a loved one suffer. For example, Lindsey Breslin, in her study on home-based care of chronic patients in Mozambique, notes how children expressed great sadness when they talked about their parents' ill-health in a focus group. She observed that the mood during the group discussions changed when the discussion was centred on their parents. The children became noticeably quieter and the mood in the room more sombre (2003: 10). Sad feelings are also felt by women caring for adult children living with AIDS. They are not only saddened by the ill-health of their children, but are distraught over the burden of caring for the grandchildren (Burt, 2003; UNAIDS/UNFPA/UNFEM, 2004). For example, in a case study in Zimbabwe on older people's attitudes/feelings about AIDS care giving, a large number of grandparents expressed great sadness at the multiple negative effects encountered in this role (WHO, 2002: 14-20). This is exemplified in the following cry by a 74-year-old grandmother caring for a grandchild:

> I feel that my role as a grandmother has changed to that of a mother in so short a time and I am not sure I have the energy to cope. At my age, I cannot continue working because my body is no longer as strong as it used to be. I am totally confused because I don't even know where to start. I have nothing and my other child who is a soldier does not support me.
>
> WHO, 2002: 19

2.3.3 Shame and stigma

As indicated earlier, AIDS psychosocially "is a chronic illness with a long term, incapacitating, terminal and stigmatizing character" (D'Cruz, 2004: 413). Beyond the anger and sadness inherent in experiences of a chronic illness, shame is an inevitable emotion in AIDS sufferers and those caring for them. This is illustrated by Fife and Wright (2000) in their study, *The dimensionality of stigma: a comparison of its impact on the self of persons with HIV/AIDS and cancer*. They found that individuals with AIDS reported stronger feelings of stigma than individuals with cancer. The difference in perception between cancer and AIDS sufferers was due to the stigmatizing character of AIDS. HIV/AIDS has acquired this strong stigmatizing character because it was initially identified with homosexuality, which is often considered to be a deviant form of human sexuality (see Catalan, 1999; Kübler-Ross, 1987). In addition, it is predominantly classified as a sexually transmitted disease and is thought to be acquired by way of immoral behaviour. This effectively holds the individual with AIDS responsible for its occurrence. In addition, it is perceived as having serious consequences for the 'Other' (Fife & Wright, 2000: 50-52). Sociologically shame, as discussed earlier, is seen as a phenomenon with substantial social roots, functions, implications and effects. Shame always requires 'the other' – an audience (Sartre, 1956 in Bartky, 1990: 85). Pattison (2000: 52) expands on this idea when he asserts that "people induce shame, it is a product of comparison with others, it affects the nature of relationships, and it can affect the whole nature of a group or society". Studies show that most individuals afflicted by AIDS, an illness associated with immoral sexual behaviour, induce and are plagued by feelings of shame (see Baylies & Bujra, 2000; Cardo, 1999; D'Cruz, 2004; Fife & Wright, 2000: 57). Beyond this morally induced shame, lack of control over bodily function is shameful for the AIDS patient and unpleasant for the carer (Steinberg *et al*., 2002: 13).

The shame attached to AIDS, can therefore be an isolating experience if one does not find ways of sharing and communicating it. Studies show that many individuals living with AIDS express the following: I feel others think I am to blame for my illness; I do not feel I can be open to others about my illness; I fear someone telling others about my illness without my permission; I feel I need to keep my illness a secret; I feel I am at least partially to blame for my illness (Cardo, 1999: 68-113; Fife & Wright, 2000: 57). Some of these feelings are shared by family members caring for the AIDS patient. As Steinberg *et al*. (2002: 23) state in their study, *Hitting home: how households cope with the HIV/AIDS pandemic: A survey of households affected by HIV/AIDS in South Africa*:

> An indication of the shame associated with HIV/AIDS, was the fact that even in their final sickness, many people preferred not to disclose their status to family members. Only half of the households surveyed said that the sick person they were caring for had HIV/AIDS. Households who were not aware of the underlying cause of the person's ill health most often mentioned opportunistic (HIV-related) infections such as tuberculosis and pneumonia.

This shameful perception results in both 'voluntary' and 'involuntary' social isolation. This is illustrated in the following typical expressions by people with AIDS (PWA): 'I feel set apart from others who are well'; 'I have a greater need than usual for reassurance that others care about me'; 'I feel lonely more than usual'; 'Due to my illness, I have a sense of being unequal in my relationships with others and sometimes feel useless'; 'I feel less competent than I did before my illness'; 'Changes in my appearance have affected my social relationships' (Fife & Wright, 2000: 23). Once again, family members are similarly affected and feel the loneliness, especially in their care-giving role. For example, Burt (2003) found loneliness and social isolation to be a common theme among the women caring for adult children with AIDS. This is exemplified in one woman's cry:

> With the first child that died my relatives used to come and visit when I was looking after her. She had cancer. Amazingly, with this one [daughter with AIDS] nobody comes around. Is it not because they are afraid of this thing? That's what I think. People are afraid of this sickness. People say they are afraid because this sickness is infectious. I think they were thinking bad thoughts about her because she had this sickness, that is why they didn't want to visit. I still wonder inside of me, why they didn't come? I have got an elder sister-in-law she stays just a few blocks from here but she never came here. When I asked her why she didn't come and visit this child she said no she can't come and be infected with HIV/AIDS. She came straight to me and she told me straight to my face that she would never come to my house because I am keeping somebody who has this dirty disease and it is infectious and she will never come here. I am so angry with her for saying such a thing.
>
> Burt, 2003: 38

The above shameful sentiments and self-perception of PWA, as well as the woman's cry, show how emotional suffering and the isolating experience of AIDS is fuelled by its stigmatising character.

The original Greek meaning of the word stigma is 'to mark or brand', and it referred to marks that publicly disgraced the person (Goffman, 1984: 116). This meaning has changed, and a person stigmatised need not be branded or marked, but simply have a 'disgraceful' illness or condition (Goffman, 1963 in Kleinman, 1988: 155-156). Like shame, stigma invokes themes and feelings of humiliation, inferiority, boundary violation, personal anguish and self-devaluation (Pattison, 2000:57). Goffman (1963 in Kleinman 1988: 159) elaborates:

> If the source of stigma is publicly visible, stigma is 'deeply discrediting'; if concealed from others, the stigma renders the affected person 'discreditable'. In either case, it is internalized as a 'spoiled identity', a feeling of being inferior, degraded, deviant, and shamefully different.

In the case of an HIV-positive status, the label of 'spoiled identity' goes beyond the patient as it affects family members. Internalisation of a 'spoilt identity' or a stigmatised label makes it a part of an individual's identity and in that way a part of the self that generates behaviour (Scheff, 1966 in Fife & Wright, 2000: 51). A negative consequence of stigma attached to HIV/AIDS is that it helps in driving the pandemic as people fear going for voluntary counselling and testing for HIV, and may unknowingly infect others or get infected themselves (MacLean, 2004: 103).

Despite the gravity of AIDS stigma, belonging to a support group and sharing one's shame helps in countering its negative effects. As Lynd (1958 in Scheff, 2000: 92) explains, "the very fact that shame is an isolating experience also means that if one can find ways of sharing and communicating it, this communication can bring about particular closeness with other persons". Research on AIDS stigma shows that, individuals who belong to support groups or who have disclosed their status to close family members and friends cope better than those who hide their status. Those who disclose may feel less isolated in their experience of AIDS. In addition, closer bonds have evolved following disclosure for some HIV positive individuals and their significant others (Cardo, 1999: 159; Steinberg *et al*., 2002: 23).

The above positive findings of HIV disclosure, nonetheless, do not stop heart-rending stories of AIDS discrimination. Most individuals with AIDS are faced with the unending task of dealing with a 'spoilt identity' and negotiating it in the interactions with others who may view their character and behaviour as immoral (Park, 2002: 21). PWA are often perceived as being responsible for their infection and are sometimes seen as a threat to the uninfected 'Other' and "the *moral* order of the world" (Turner, 1984: 36). Thus, being HIV negative is implicitly taken as a sign of morality and may give one a sense of entitlement to pass moral judgement on HIV positive individuals. This has on occasion led to the worst case scenario of AIDS stigmatising – being killed for being HIV positive. As Ferreira (2004: 5) quoting a report in the Cape Argus newspaper, illustrates, instances of overt discrimination, including violence, happens:

> On December 13, 2003, in Khayelitsha, a sprawling township outside Cape Town, South Africa, a 21 year old HIV positive AIDS educator, Lorna Mlofana was beaten to death after telling a group of men in a shebeen [tavern] who had just raped her of her status. The Treatment Action Campaign (TAC) thereafter took to the streets in the township to demand that the community and the police make it a priority to apprehend her murderers.

> ‘We HIV positive people are stigmatised, we are insulted, we are beaten’ said a protestor. ‘Our people hate us’.

From this, it can be concluded that the real or imagined fear of being harmed physically when one discloses one’s HIV positive status and the accompanying stigma exacerbate feelings of isolation and loneliness for PWA. HIV stigma has a devastating impact on selfhood and adds to the illness experience of AIDS. Furthermore, this fear of being harmed emotionally or physically helps in driving the epidemic and is “proven to be perhaps the most difficult obstacle to effective HIV prevention” (UNAIDS/WHO, 2005: 10).

2.3.4 Fear

Fear associated with living with a chronic or serious illness often involves the emotional and physical pain in the dying process. For example, Gordon Stuart, 33 years old, dying of cancer, talks to Kleinman (1988: 147) about his fear of dying:

> Today it’s the fear all over again. I don’t want to die. I’m only thirty-three; I’ve got my whole life to live. I can’t be cut off now. It isn’t just. Why me? Why now? You don’t have to answer. I’m just in a lousy mood right now. You get maudlin and morally weak waiting for the end. I’m usually pretty good aren’t I? Only sometimes something young and scared breaks out. Otherwise I’ve become like an old man, preparing myself – but over weeks, not years.

Even though death has a definite character, in the sense that we all know that we will die, we may not know how much suffering our dying will impose, both on ourselves and on our loved ones (Riezler, 1944: 490). The knowledge of how diseases such as cancer and AIDS inflict horrendous pain despite medical intervention, feeds into “our fear of death, which blends with our fear of our suffering in dying” (Riezler 1944: 489). In the case of PWA, the fear of death is in addition to the fear related to AIDS stigma discussed above. This is illustrated by a 71-year-old man, who is both HIV positive and has cancer of the prostate:

> I felt very anxious when I thought of AIDS because of the suffering. Physically, it is a frightening disease. I did feel a degree of fear thinking about it … It did worry me, more so than the cancer, because with AIDS there is that notable physical suffering. The image of death has been with me for a while … I won't say that I was happy about it but I had come to terms with death. I am dying. The dying aspect was of less importance to me. The evil, the sin [referring to stigma attached to AIDS], the why does God do this to me … That God had abandoned me. The punishment – it is what society and the church tells you.
>
> Jan, 71 years old, in Cardo, 1999: 212-213

Another participant in the same study echoes these sentiments:

> Thinking about AIDS and dying horribly made me feel scared … I thought of death. I knew that when a person has AIDS they die horribly.
>
> Mercy, 27 years old, in Cardo, 1999: 217

Dying parents have fears beyond their impending death. Parents' fear for the welfare of their children appears to be a common theme when reviewing qualitative studies on HIV/AIDS. Nearly all individuals with this predicament are fearful of the impact their death will have on their children (e.g. Breslin, 2003: 11-12; Cardo, 1999: 163, 216; Russel & Schneider, 2000:15). In sub-Saharan Africa, this includes the welfare of elderly parents, especially grandmothers who are burdened with care-giving responsibilities (UNAIDS, 2004; UNAIDS/UNFPA/UNIFEM, 2004). A study commissioned by the WHO (2002) on *Impact of AIDS on older people in Africa: Zimbabwe case study*, identifies factors that negatively impact on the care-giving ability of older people and are a source of great trepidation:

> The financial burden of care, the physical demands of care-giving, a lack of knowledge about AIDS-related care, a lack of medicine, the mental and psychological stress of care-giving, a lack of food and other basic needs, poor access to health care for the sick as well as for older care-givers, socio-cultural issues like stigma, abuse, abandonment and neglect … Apart from this, care-givers also had to personally deal with their own fears of contracting the disease, as well as the frustrations inherent in performing the daily chores of cleansing, washing and feeding the PWA and orphans, with no obvious external assistance.
>
> WHO, 2002: 14-15

Similarly Russel & Schneider (2000), in a study *A rapid appraisal of community-based HIV/AIDS care and support programs in South Africa,* found that both infected parents and providers are concerned about the children and what will happen to them when their parents die. This is epitomised in the following lament of a male participant:

> You know right now I can contribute to my family. I get the disability grant of R450 per month, so I can buy some mealies, or I will go and ask people for food to feed my family, but soon I will die and there will be no more money. My wife is shy. She will not be able to go out and ask for food. I have a son, they will starve, my wife will die and where will my son go? Probably to a relative who will treat him like a slave, speak roughly to him. They may not share food and when will he study? What am I going to do?
>
> Russel & Schneider, 2000: 15

A 62-year-old woman, looking after three orphaned children in Bulawayo, Zimbabwe, expresses a similar fear:

> I am so afraid of what the future has in store for these orphans. If I were to die and leave them, there would be no-one to look after them.
>
> WHO, 2002: 9

The reality of the above is shown in the growing number of child-headed households in sub-Saharan Africa. For example, the Nelson Mandela/HSRC (2005: 113) national HIV/AIDS prevalence survey reports a doubling of child-headed households, from 1.5% in 2002 (NelsonMandela/HSRC, 2002) to 2.6% in the current study. According to this, it means that 213 859 orphaned children in the South African population are heads of households (NelsonMandela/HSRC, 2005: 113). These findings are similar to other sub-Saharan African national surveys on child-headed families. According to current estimates, 12 million children in sub-Saharan Africa live without parents (UNAIDS/WHO, 2005: 17-30; UNICEF, 2005: 6).

The fear of death of a parent or principal care-giver (grandmother) is mutually shared by the children. This is a universal fear whether parents have AIDS or not. For example, research findings in six countries – Australia, Canada, Egypt, Japan, the Philippines and the United States of America – show how children are remarkably alike in the things they are afraid of. The study showed that the primary fear among children in each country was the same: “the fear of losing a parent” (Yamamoto, *et al*. 1987 in Papalia & Olds, 1992: 299). This finding is echoed in studies on children with a parent/s dying of AIDS. For example, Breslin (2003) in her study *A research study on home based care in Mozambique,* found that children (aged 8-12) expressed worry when one of their parents fell sick and they talked about the insecurity surrounding their future. One of them said: “When my father became sick, I imagined he would die and we would suffer”. Another child stated: “I thought my father would marry another woman, and we wouldn’t be taken care of well”. This child was talking about his sick mother and her looming death.

The above review shows how HIV/AIDS impacts on the families across generations. AIDS interferes with a parent's ability to provide adequately for children, both physically and emotionally. Due to illness or death of a parent, primary care responsibilities fall on extended family members. In most instances, grandmothers become the primary care-givers for multiple children (Burt, 2003; Ferreira, 2004: 2-3; WHO, 2002). In addition the vulnerability of children affected by AIDS starts well before the death of a parent. Children affected by AIDS will often experience many negative changes in their lives and can start to suffer physical and emotional neglect, long before the death of the parent or care-giver (Breslin, 2003: 9-16; Germann, 2004). The emotions of anger, sadness, fear and shame discussed above are not exclusive to illness experiences or care-giving experiences, they are ubiquitous when compounded with poverty, as the stories of the six women in this study shows.

2.4 Concluding comments

Given the pervasiveness of emotion in everyday life, especially during times of chronic illness and poverty, a meaningful way of understanding the experience of living in such conditions entails a phenomenological exploration. This means focusing on an area of existence that individuals, such as the three generations of women in this study, have expertise on, namely their emotional selves. It is through their subjective and intersubjective emotionality that their own as well as the researcher’s understanding, interpretation, and meaning of their lifeworld is located. For the women, it includes emotional narratives arising from their inferior location in society and the effects this has on their selfhood. It is therefore necessary to understand how emotionality as a form of consciousness is lived, experienced, articulated, and felt by study participants. The literature reviewed in this chapter has determined themes and questions which frame and guide the methodological procedure of the study, as well as the interpretation of the narratives. In the following chapter, I will continue to demonstrate how living with a serious illness, and the related emotions, disrupt established concepts of the self.

CHAPTER 3

EXPERIENCING CHRONIC ILLNESS AS A BIOGRAPHICAL DISRUPTION

3.1 Introduction

This chapter looks at how living with a chronic or serious illness disrupts the lifeworld of the individual. The reviewed literature shows how chronic illness is experienced as a ‘critical situation’ not only for the physical suffering, but for the accompanying ontological uncertainty it inflicts on individuals (Lawton, 2003: 25). The latter relates to the sense of disruption by something which is perceived to be beyond the control of the individual, beyond fairness and beyond logic, and of being forced into an awareness of insecurity (Crossley, 2000: 78-89; Kleinman, 1988: 29; Murray, 2000: 339-340). The ontological uncertainty that individuals living with a chronic or serious illness feel is addressed in terms of their biography and their stock of common knowledge about health and illness (Radley, 1993: 109). The disruption affects how one views one’s self-identity, and has led to the formulation of concepts such as ‘biographical disruption’ (Bury, 1982: 167-182), and ‘loss of self’ (Charmaz, 1983: 167-198). A common thread running through these concepts is that the most basic, underlying existential assumptions that people hold about themselves and the world are thrown into disarray during a serious or chronic illness. Another shared assumption is that the onset of physical illness brings with it a whole range of challenges regarding the individual’s interconnected conceptions of the body, the self and the world. This includes a basic sense of space, time and language (Crossley, 2000: 82-83).

Biographical disruption due to an illness goes beyond the affected individual, because “the experience of illness is not bounded by the bodies or consciousness of those who are ill, it reaches to encompass a household, a family, or a social network” (Kleinman & Seeman, 2000: 231). The suffering is thus not only located in the individual with the illness, but in those closest to her/him, as the stories of the three generations of women in this study show. For this reason, literature on the impact of the illness on family members and their role as primary support for the ill individual is included in the discussion. Also discussed are other coping support systems, such as religious institutions, medical care, social grants, and NGOs.

3.2 The disrupting effects of chronic illness on the individual

Commentators suggest that during an illness, it is not just the body but our very identity that is threatened, and disrupted (Bury, 1982; Charmaz, 1983; Kleinman, 1988). In this sense chronic illness can be understood as disturbing not only one's embodied self but "the trajectory of one's whole life at a number of levels" (Nettleton, 1995: 88). This is shown in Bury's (1982: 167-82) study *Chronic illness as biographical disruption*. The study is based on semi-structured interviews with rheumatoid arthritis (RA) patients, and intentionally focused on those who had been recently diagnosed with RA. Bury's aim was to highlight the complex ways in which the experience of chronic illness can lead to a fundamental rethinking of a person's biography and self-concept. His contention is that chronic illness throws the structures of everyday life and forms of knowledge which underpin them into disruption (Bury, 1982: 169). This view is echoed by others, for example, Charmaz (1983: 168) in her study *Loss of self: a fundamental form of suffering in the chronically ill,* describes the participant's experience of "former self-images crumbling away" due to a variety of chronic diseases. She goes on to note how the experiences and meanings upon which ill individuals have established positive self-images elude them. In time, this leads to a diminished self-concept, that is, a 'loss of self' (ibid.).

As Bury (1982) and Charmaz (1983) illustrate, 'biographical disruption' and 'loss of self' due to chronic illness takes place on many different levels. For example, arthritic pain can instigate "a new consciousness of the body, and of the contingent and tenuous nature of one's (embodied) existence" (Lawton, 2003: 25). This means that chronic illness brings about a new and vibrant awareness of the body, which "involves a recognition of the worlds of pain and suffering, possibly even death, which are normally only seen as distant possibilities or the plight of others" (Bury, 1982: 169). In addition, Bury (1982) highlights the disruptive effects that chronic illness has on relationships, material and practical affairs. Other writers have also pointed out that our experience of illness is “fundamentally inter-subjective” (Kleinman *et al*. 1992 in Crossley, 2000: 86). This means that it is not just the individual living with an illness, who is affected, but also the lives of family members and others close to the individual. In the case of debilitating illnesses such as rheumatoid arthritis, physical dependency on others becomes a norm and this disrupts “normal rules of reciprocity and mutual support” (Bury, 1982: 169). Like Bury, Charmaz (1983: 169-70) highlights how a ‘loss of self’ is a multifaceted experience for her study participants. She notes that by virtue of their illness, the participants often led restricted lives, experienced social isolation, were discredited by self and others, and experienced the humiliation of being a burden on others.

The inability to reciprocate in social interactions and the progressive physical dependence on others exacerbate the suffering of the ill individual and affects how the illness is experienced. For example, D’Cruz’s (2002: 413-34) study *Caregivers’ experiences of informal support in the context of HIV/AIDS* shows the negative feelings associated with being in a position of dependency because of ill-health. Participants in this study noted that they felt the need to reciprocate the help received, either physically or emotionally. This is their way of affirming their social significance, as well as a way of compensating for their predicament. This feeling was articulated by both AIDS patients and their care-givers. Dependency on others also intensifies the shame and other emotions related to being HIV positive, as discussed in Chapter 2. All this points to the complex and overlapping ways in which different aspects of the illness experience (e.g. emotional anguish, pain, strain on relationships, social isolation, etc.) may reinforce and amplify one another (Lawton, 2003: 26). For example, Charmaz (1983) observed how ‘loss of self’ in one area of her participants’ lives often spiralled into a loss of another aspect of their lives, with serious negative consequences. To illustrate, she notes how stigma associated with a chronic illness causes individuals to experience feelings of low-self-esteem and withdraw from social activities. The latter in turn, may exacerbate feelings of ‘loss of self’, as this “leads to fewer opportunities for constructing a valued self” (Charmaz, 1993: 172).

3.2.1 Does collectivism (Ubuntu) help?

It must be pointed out that the consequences of illness on self and identity, on the loss of self or of control, and on biographical disruption may not be universal (Pierret, 2003: 9-10). Most research on the devastating experiences of chronic illness on self-identity has been carried out among Westerners (e.g. Bury, 1982; Charmaz, 1983; Ezzy, 1998; Fife & Wright, 2000; Williams, 1984). Non-Western philosophies and ways of being in the world may influence how the onset of a serious or chronic illness is experienced and it may influence the meaning of the illness on selfhood. This, in part, is due to the collectivist nature of the social context in non-Western societies (D'Cruz, 2004: 421). In these societies interdependency, for example the Southern African concept of ubuntu, is privileged over Western independence and self-autonomy (Ramose, 2002: 237). Ubuntu is a worldview where "the distinctive collective consciousness of Africans is manifested in their behaviour patterns, expressions, and spiritual self-fulfilment, in which values such as universal brotherhood of Africans sharing and treating other people as humans are concretised" (Khoza, 1994 in Prinsloo, 1998: 41). This philosophy is captured in the common saying "I am because we are: I exist because the community exists" (Gbadegesin, 1998: 293). Therefore, the individual's illness and its devastating consequences are shared by the collective, especially the family. For example, D'Cruz (2004) in another study *The family context of care in HIV/AIDS: a study from Mumbai, India* found that familial values underpinned care-giving behaviour towards AIDS patients. The participants expressed "innumerable reasons such as a sense of duty, love, lack of choice, humanitarian concern and social reasons" (D'Cruz: 2004: 421) as motivation for care-giving. All this may cushion the negative impact of illness on self-identity felt by patients in individualistic societies.

3.2.2 What about poverty?

Beyond the cushioning effects of collectivism, living in chronic poverty and its negative consequences or other 'disruptive life situations' (Ciambrone, 2001: 517) may also minimise the upsetting impact of a serious or chronic illness on the self-concept. This is illustrated in Ciambrone's (2001) study *Illness and other assaults on self: the relative impact of HIV/AIDS on women's lives*, in which the participants were purposively drawn from poor, HIV positive African-American women with drug and other related problems. Despite the fact that HIV infection posed an immediate threat to their sense of self and had a lasting impact on their future plans and goals, retrospectively 71% of the study participants did not consider HIV to be the most disruptive event in their lives (Ciambrone, 2001: 532). This is expressed well by one woman who describes her former violent and abusive intimate relationship relative to her HIV positive status:

> I would say the hardest time was the abuse… Because when you are in an abusive relationship, your body's just dead. It's just like a robot, that's doing what it has to do. Compared to just living with HIV, I would rather live with having AIDS and HIV any day compared to being abused… When you are abused you are nothin', I had nothing. I had no feelings, I had nothing, I was just one cold person.
>
> Ciambrone, 2001: 522

Thus, Ciambrone (2001: 532) and other researchers, especially in poor countries (e.g. Baylies & Bujra, 2000; D'Cruz, 2002, 2004; Feldman, Manchester & Maposhere, 2002; Wallace, 2004 in ICW, 2004) conclude that "HIV may be just another in an ongoing string of disruptive events". In addition, widespread poverty and political problems in sub-Saharan Africa, South Asia and other developing regions mean that illness narratives are sidelined in research in favour of macro-problems, such as:

> Extreme disempowering and debilitating poverty; economic recessions, foreign debt, the effects of economic structural adjustments programmes, and massive unemployment; underdevelopment and poor infrastructure; weak leadership, poor governance and corruption; political instability, conflict and violence; pervasive patriarchy, with women discriminated against and disadvantaged; the effects of droughts, floods and pestilence on agriculture; livelihoods and food security; and rampant disease, including malaria, tuberculosis, waterborne disease and malnutrition – and now HIV/AIDS.
>
> Ferreira, 2004: 1

This overrepresentation of macro-issues does not however, deny the existence of individual suffering among Africans or Asians, as this study attempts to highlight. Other similar studies in sub-Saharan Africa show that 'biographical disruption' or 'loss of self' concepts may well be utilised in the interpretation of the negative effects of chronic illness on selfhood and relationships (see Cardo, 1999). For, indeed, the onset of a major illness, let alone a chronic one, necessitates a rethinking of one’s established lifeworld and the disrupting effects on selfhood and relationships, regardless of one’s social context and worldview.

3.3 Dealing with the disrupting effects of a chronic illness

In recent years social science researchers have been looking at how people cope with the disruptive effects of chronic illness through storytelling and the processes of ‘narrative reconfiguration’ or ‘narrative reconstruction’ (Kleinman, 1988: 144-145; Williams, 1984: 175-200). These concepts of narrative reconfiguration or reconstruction refer to the “use of different forms of story which function to re-establish a moderate degree of ‘ontological security’, a renewed sense of meaning, order and connection in the individual’s life” (Taylor, 1983 in Crossley, 2000: 78). Ontological security is the sense of security in one’s own being and having a sense of being a whole person. Laing (1965: 39) describes ontological security in the following way:

> A man may have a sense of his presence in the world as real, alive, whole, and in a temporal sense, a continuous person. As such, he can live out into the world and meet others: a world and others experienced as equally real, alive, whole, and continuous. Such a basically ontologically secure person will encounter all the hazards of life, social, ethical, biological, from a centrally firm sense of his own and other people’s reality and identity.

The above conception of an ontologically secure self is often disrupted at the onset of a serious or chronic illness, as discussed above. Gareth Williams in his study *The genesis of chronic illness: narrative re-construction* demonstrates how people’s beliefs about the cause of their illness “need to be understood as part of the comprehensive imaginative enterprise”, which he refers to as “narrative reconstruction” (1984: 175). Like Bury (1982), he also conducted his study on 30 individuals with rheumatoid arthritis (RA), but his focus was on how participants made sense of their disrupted selves. What stories were they telling about the cause of their illness? He found that the question: ‘Why do you think you got arthritis?’ was translated by participants into a narrative reconstruction of their changing relationship to the world in which they live and the genesis of illness within it (Williams, 1984: 175). Based on the participants’ responses, Williams (1984: 180) devised three themes to illustrate how distinctive narrative forms are reconstructed to account for the cause of the illness, as well as making sense of the illness experience: (1) narrative reconstruction as political criticism, (2) narrative reconstruction as social psychology, (3) the transcendence of causality and narrative reconstruction. Let us focus on these three themes.

3.3.1 Narrative reconstruction as political criticism: resistance against gender oppression

For this theme, Williams (1984) draws on the story of Bill, a 58-year-old man, retired on account of ill-health and suffering from RA. He is a former factory worker who served in the British army as a paratrooper, and he has a history of arthritis and rheumatism in his family. What was significant about Bill's narrative is his adamant position in locating the genesis of RA within the work environment. He claimed that his RA was "chemically induced", because "I worked with a lot of chemicals, acetone and what have you. We washed hands in it, we had cuts, we absorbed it" (cited in Williams, 1984: 181). He refused to accept the doctor's diagnosis that his RA may be genetically constituted. To support his stance, he pointed to the 'revolts' that used to happen at his factory in protest of the hazardous working conditions. The factory, apparently, accepted liability and paid compensation. From this, Williams (1984: 185-87) concludes that:

> Both the illness and the response of the professionals to it, suggest a world of power inequality in Bill's narrative reconstruction. *Further*, Bill recognized that technology and science are ideological, and that medicine can support political bureaucracy in preventing the establishment of social justice. Bill's narrative reconstruction articulated a nascent political criticism of the way of life of modern society in which the genesis of his own misfortunes and those of others could be understood as the product of malevolent social forces. *Thus*, modern society is seen as a locus of exploitation, bureaucratic silence and multiple frauds upon the laity, where personal troubles are also public issues requiring political intervention [emphasis added].

Other studies have come across similar 'political narrative reconstructions' of the cause of illness. For example, most women living with AIDS, especially in poor countries, explain their illness within the feminists' concept of 'sexual politics' (Baylies, Chabala & Mkandawire, 2000: 99-102). This is due to the fact that AIDS, at its core, is a crisis of gender inequality, with women less able than men to exercise control over their bodies and lives (Feldman, Manchester, & Maposhere, 2002: 22-33, 52-53; UNAIDS/UNFPA/UNIFEM, 2004: 7-9). As feminists point out, patriarchal domination in society means that cultural expectations encourage men to have multiple partners while women are expected to abstain or be faithful. Thus by merely fulfilling their expected gender roles, men and women are likely to increase their risk of HIV infection (Baylies & Bujra, 2000: 7-8).

For women in poor countries, especially, gender inequalities go beyond sexual relations in making them vulnerable to HIV infection. Economic dependence on men is seen as one of the greatest threats to women's physical and mental health (UNAIDS/UNFPA/UNIFEM, 2004: 7-9). In the case of HIV protection, they risk violence if they insist on safe sex or abstinence. Economic need also drives some women into sex work where the risk of HIV and other sexually transmitted diseases is great (Amuyunzu-Nyamongo, 2001: 90; Baylies & Bujra, 2000: 5-13; ICW, 2004: 2-5; Sikwibele, Shonga & Baylies, 2000: 68-74). Narrative reconstruction therefore, for a woman living with AIDS whose social context is similar to these, will be heavily weighted towards a socio-economic and socio-political interpretation for the genesis of her AIDS. For example, a young woman, orphaned by AIDS and herself HIV positive, had this to say on how she became infected:

> My father had left no pension, so I had to find ways to look after the family. I had three brothers and a sister, who died when she was three years old. There was no other way to find money. I started to have sex with any one who could give me money. It was not easy for me but I had to do it because I had to find food for my brothers. All the relatives did not want to help us. …Before I knew my HIV status I did not try to protect my self from getting AIDS. I had no choice. I had to feed my brothers and that time I was 18 years old.
>
> Feldman, Manchester & Maposhere, 2002: 40, 51

As discussed in Chapter 1, gender inequality and poverty not only increase the risk of HIV, but also leave women more vulnerable than men to its impact. Short term survival needs force women to develop a range of coping strategies with varying implications for long-term health and well-being. It is for this reason that “many women, especially in rural sub-Saharan Africa, define poverty as their primary concern above all others, including the risk or reality of HIV” (Wallace, 2004 in ICW, 2004: 2). Therefore, contracting HIV and having AIDS for women living in dire circumstances is explained and located in their social context, that is, patriarchal domination and chronic poverty (Feldman, Manchester & Maposhere, 2002: 21-48; ICW, 2004: 2-7; UNAIDS/UNFPA/ UNIFEM, 2004: 11-22, 31-38, 45-50).

3.3.2 Narrative reconstruction as social psychology: the effects of womanhood on health

In this theme, Williams (1984) draws on Gill’s story to explain the social psychological or sociological factors involved in the reconstructions of women’s genesis of RA. Gill was a middle-aged school teacher living in a wealthy and conservative suburb. In contrast to Bill, whose illness account encompassed social relations yet left out any reference of the genesis of his illness to his identity or self, Gill’s account locates the cause of RA within a web of stressful events and processes, that is, within herself. She saw her illness as the bodily expression of a suppression of herself in the process of being a wife and a mother. The stressful familial events that precipitated her illness in a twelve-month period are: her daughter leaving home in distressing circumstances; her husband becoming seriously ill and eventually dying; a rapid onset of RA (from ambulant to bedridden within 36 hours); her youngest son being killed in a motorcycle accident and finally, as a consequence, the loss of her longstanding belief in God (Williams, 1984: 189). Since her sense of ontological security was so firmly rooted in the context of familial relationships, the disruption in those relationships led to “an intimation of pointlessness, the development of illness, and the obliteration of all metaphysical referents” (Williams, 1984: 190).

Like Gill, some women use sociological explanations of why various illnesses develop. For example, Elvira, a 53-year-old coloured woman living in Mamre, a small poverty stricken village near Cape Town, explains her ‘high blood pressure’ and other related ailments as being caused by her home situation. Her five grown children, a daughter-in-law and ten grandchildren all live with her and her husband, in an old, ramshackle house. Only her husband and one son are employed, while Elvira is responsible for looking after the grandchildren and the housework. There is a lot of alcohol abuse in the household, which disturbs Elvira emotionally, psychologically ('nerves') and physically (blood pressure, upset stomach and stomach pains). Thus, for Elvira, the social and interpersonal difficulties are inextricably tied up with her illnesses (Rogers, 1992 in Swartz, 2000: 140-42). The stories of Gill and Elvira are almost universal, because the nature of domestic labour often affects women's health:

> Household work and child-care can be exhausting and debilitating especially if they are done with inadequate resources and combined, as they are for many women, with pregnancy and subsistence agriculture. It can also damage mental health when they are given little recognition and carried out in isolation. The time consumed by caring for others leads to neglect by women of their own health. For women, domestic life and labour also carry the threat of violence since the home is the arena in which they are most likely to be abused. The emphasis on their domestic roles also means that women suffer more severe consequences than men when a family member is a substance user or if they use substances themselves.
>
> UNDAW, 1998: 107-112

The negative effect of household labour on women is summed up in Gill's words when she talks about her 'stress' which precipitated her RA:

> Not simply the stress of events that happened but the stress of perhaps suppressing myself while I was a mother and a wife; not 'women's libby' but there comes a time in your life when you think, you know, 'where I have got to? There is nothing left of me'.
>
> Cited in Williams, 1984: 188

From this, it can be concluded that the social process of womanhood, specifically motherhood, disrupts not only the physical female bodies, but their emotional and psychological being as well. Thus, in the understanding and explanation of illness experiences, certain women see their ill-health as a consequence of their household situation (Swartz, 2000: 142; Williams, 1984: 189).

3.3.3 The transcendence of causality and narrative reconstruction: illness as divine decree

Williams' (1984) third theme is based on Betty, in her early sixties, suffering from RA and unemployed due to ill-health. She, like Bill and Gill, suffers from chronic pain, which affects 'normal' functioning involved in day-to-day living. She was unable to hold on to her much-needed job, to wash and dress herself and to sleep in the same bed with her husband. Despite all this, Williams observed how she "appeared remarkably composed" (1984: 193). Her serenity in the face of all her hardships and illness is rooted in her firm belief in God. It has been observed that "when God is a powerful feature of an individual's cosmology His existence may be adduced not as a cause of the illness but as good reason why, in matters of illness and other misfortunes, the believer is not granted automatic exemption" (Williams, 1984: 193). In such a case, as evidenced in Betty's story, "the individual may be liberated from the burdens of narrative reconstruction and causal analysis and left free to indulge their lyrical sensibilities" (ibid). This is shown in Betty's matter of fact statement: "Look, I don't question the Lord, I don't ask …. He knows why and that is good enough for me". She goes on to point to her 'good fortune' of being born in a country (England) that has good medical care as an indication of God's providence. From this, one may interpret that Betty sees her plight, RA and being born in a good country, as pre-ordained by God and that her job is simply to accept God's will (Williams, 1984: 194).

Other studies have similar findings. For example, Somlai and Heckman (2000: 57-70) in their study *Correlates of spirituality and well-being in a community sample of people living with HIV disease*, note how a large number of their participants believed that "a higher power cares for them" and that "AIDS is not a divine retribution". Somlai and Heckman (2000) noted that believers were more likely to develop coping strategies for their illness. The researchers found a correlation between religiosity and active problem solving, such as seeking support from family and church members. This has a positive impact on their emotional well-being, as religiosity buffers the negative consequences of AIDS stigma, fear, sadness, shame, social isolation, etc. In addition, some believers have a sense of purpose for life and live with the attitudes of commitment and control. They create meaning in illness or hopeless situations by striving for a deeper understanding of that which lies beyond the self (de Kooker, 2004: 23). As Williams (1984: 193) and others conclude, narrative reconstruction located in an omnipotent Being, where "the central meaning of life is defined by some transcendent principle" shows that "there is a set of religious truths that do not require further investigation or analysis" (McAuley, Pecchioni & Grant, 2000: 20). This conviction provides existential or ontological security and a sense of meaning and purpose for the believers, both in illness and in health. For believers then, "God ameliorates the effects of illness or makes illness easier to accept or to manage" (ibid.: 22).

The preceding three themes are among other coping strategies that individuals utilise in attempting to explain and deal with their 'disrupted biographies' or 'lost selves' due to a serious or chronic illness.

3.4 Coping strategies

In addition to the above narrative reconstruction themes and the emotional experiences discussed in Chapter 2, individuals need to initiate strategies for coping with everyday taken-for-granted practical routines that are disrupted by illness. These individuals will utilise various resources as coping strategies to reorganize their daily lives (Pierret, 2003: 11). The primary source of help for most individuals is social support, mainly from family members. Familial support is especially common in poorer societies, and is supplemented with religious based organisations and NGOs (Mbilinyi & Kaihula, 2000: 83-89; McAuley, Pecchioni & Grant, 2000: 13-23; WHO, 2002: 22). Governmental support in the form of health-care systems is also utilised, especially in societies with adequate medical resources.

3.4.1 The role of the family

To repeat an earlier point, chronic illness impacts not only on the individual but also on the family and forces several adjustments within the household. It is for this reason that the family unquestionably represents the first line of emotional and material support (Pierret, 2003: 11-13). This claim is supported by a study on HIV/AIDS which shows that 80% of the respondents who revealed their status to their families received support and acceptance by the family (Steinberg *et al*., 2002: 23). Similarly, D'Cruz's (2004) earlier cited study on family care-giving for AIDS sufferers in India shows that familial values underlie support and care given to an ill family member. Participants, both care-givers and AIDS patients, gave several reasons as motivations for seeking and giving care within the family. These include a sense of duty, love, lack of choice, humanitarian concern and social reasons.

Other studies, mainly in the poorer countries, also show that these family ties "are instrumental in providing caregivers with the tenacity and grit to go on with their role in the face of acute burden" (D'Cruz, 2004: 421; WHO, 2002: 12-14). Whyte and Whyte (2004: 76-92) in their study *Children's children: time and relatedness in Eastern Uganda* show how AIDS has touched every family one way or another and how "everyday life is very much about mobilising and balancing resources and support, in the idiom of relatedness" (ibid.: 78). For these Ugandans, as is the case with most non-Westerners, seeking care within the family is a matter of course, since "kinship is like your buttocks, you can't cut it off" (ibid.: 77). This is a Ugandan saying that shows the intrinsic nature of kinship to an embodied self, both in illness and in health.

Another study in Zimbabwe on the impact of AIDS on older people shows how familial obligation and emotional attachment forces family members to be the primary source of help for AIDS sufferers. The question: 'How and why do older people become care-givers: by choice or circumstance?' (WHO, 2002: 12) drew responses that echoed D'Cruz's (2004) and Whyte & Whyte's (2004) participants' reasons for seeking and giving care within the family set-up. The general consensus among care-givers was that caring is a sign of love and that the family had no choice but to look after their sick member (WHO, 2002: 12-14). As shown in Chapter 1, a major limiting factor for supporting PWA within families is chronic poverty (Aliber, 2001; CPRC, 2004-05; Ferreira, 2004; ICW, 2004; WHO, 2006). It is for this reason that PWA seek help from other sources.

Studies show that when familial support is inadequate, withheld or non-existent, help is sought in other social relations. This is the case especially in communities where medical care is not readily available. For example, a study by Bechtel and Apakupakul (1999: 471-475) *AIDS in southern Thailand: stories of krengjai and social connections*, illustrates how 'krengjai', a concept similar to the earlier discussed southern African 'Ubuntu', enables AIDS patients to seek help in other social relations. In this case, PWA sought help at the Buddhist monastery, where they connected with the monks and other AIDS patients in the spirit of krengjai. At the time Bechtel and Apakupakul's study was conducted, AIDS in Thailand was synonymous with leprosy and other physically debilitating diseases which isolate the infected from their families and society (ibid.: 472). Other studies also show social isolation due to the stigmatising nature of AIDS (e.g. Breslin, 2003; Burt, 2003; ICW, 2004; WHO, 2002). However, there are indications of improvement in this negative perception of HIV/AIDS, due to extensive AIDS education and advances in anti-retroviral treatment (UNAIDS/WHO, 2005: 6-16).

3.4.2 The role of religion

After the emotional and material support available within the family, religion is the next most common coping tool among those affected by AIDS, particularly among the poor. The above cited study in Thailand shows how socially isolated AIDS individuals use religion as a coping tool by seeking help from Buddhist monks. The Buddhist temple serves both as a community centre and a place of worship. This is the case in Christian churches, Muslim mosques, and in other religious centres of worship. Buddhist monks fulfil an essential role in the Thai communities by serving as spiritual leaders, educators and healers (Bechtel & Apakupakul 1999: 472). This trio role of religious leaders is found in other religions as well. For example, the above cited Zimbabwean study (WHO, 2002) shows how Christian churches emerged as institutions of great importance to the participants. For them, going to church for counselling, religious practices and at times for material support, were identified as channels for releasing tension and managing stress. Their faith and dependence on God were recognised as a fundamental pillar, a way of coping with the burden of AIDS (WHO, 2002: 22).

However, there is evidence suggesting that religious teachings and practices have complex effects on health, as well as a coping strategy. As discussed in Chapter 2, HIV/AIDS stigma has roots in religious teachings. This is shown in Gennrich *et al.*'s (2004) study *Churches and HIV/AIDS: Exploring how local churches are integrating HIV/AIDS in the life and ministries of the Church and how those most directly affected experience these*. The researchers in this study observed that in spite of the professed strength and comfort derived from being a member of a church, individuals living with AIDS and their care-givers also confessed to a number of negative experiences in their churches.

This ambivalent relationship with the church is shown in the story of one participant, who recounted her experience with the minister of her church before she disclosed her HIV status. She noted that he used to lay hands on her in prayer and was very warm and encouraging. In time, she decided that she could trust him, and disclosed her HIV status. Although he continued to visit her, his behaviour changed. He rarely prayed for her and he never touched her again, not even to shake her hand in greeting. She soon left that church. This negative experience is echoed by others in this particular study: "The church is the LAST place I would ever disclose my status" and yet another: "People in the church talk a lot. They must stop". One participant has even stopped praying: "I don't pray anymore, and I don't believe that God is there for me. Otherwise, what type of sin did I commit to make him so angry" (Gennrich *et al*., 2004: 23, 27-28). This finding led these researchers to point out an underlying pattern:

> We have seen a tendency among many of the ministers and lay leaders towards judgmental attitudes and theological understandings, with reference particularly to how people get infected, and why God is allowing the epidemic to happen. These attitudes involve blaming the individual person who is HIV+. Although this is not paralleled with a dominant theology among clergy (only four believed this) that says that HIV is a punishment from God, for some reason many PWA believe it is, and more believe that their ministers believe it is.
>
> Gennrich *et al*., 2004: 41

In the above quote, it is evident that PWA internalise some of the harsh and misguided theological beliefs, which may lead to a strong tendency to self-blame and self-stigmatism. Religion, therefore, can be both a cause of great physical and psychological pain or can be utilized as a tool to cope with the existential and material devastation caused by a serious illness (Oman & Thoresen, 2003: 223-29). In addition, mental stress can be caused by feelings of failure to live up to the tenets or commands of religious beliefs. This feeds into an individualistic worldview and locates health issues and responsibility in the individual – i.e. ill-health is seen as a result of personal sin or lack of faith (Gennrich *et al*., 2004: 37-39). Feelings of hopelessness are also born out of religious teachings. There is, therefore, a need to interrogate the supposedly beneficial consequences of believing in a God in the absence of the physical assistance from the Church or state to those living in poverty or with a chronic illness.

3.4.3 Medical care and government social grants

For most ill individuals in poor countries, specifically for those living in rural areas, access to adequate medical care is practically non-existent or scantly available. According to the WHO (2006: 19-37) report, there is a massive scarcity of medical personnel in most developing countries in addition to insufficient medical facilities, medication and other services. Despite this inadequacy, studies show that people living with AIDS or any other illness in these communities do seek medical intervention (UNAIDS/UNFPA/UNIFEM, 2004: 23-29). An important highlight from these studies is the gender inequality in accessing of medical care and services. For example, in a rural town in Zambia, of the forty people on anti-retroviral treatment, only three were women. This, despite the fact that well over half, as high as 70%, of the Zambians living with HIV/AIDS are women (IRIN/PlusNews, 2004 cited in UNAIDS/UNFPA/UNIFEM, 2004: 23). The unequal access to medical care can be partially explained in terms of the feminist stance on patriarchal domination, discussed in Chapters 1 and 2. This is illustrated by the women in the above cited Zambian town who reported various reasons for not accessing treatment, including the following:

- Discrimination: Where money was limited, families often chose to pay for medication for the men in the household rather than the women;
- Property rights: One couple who could only afford treatment for one of them told reporters that if the husband died, his family would inherit his land and his wife would have no way to support their children. If the wife died, he would still have the land.

IRIN/PlusNews, 2004 cited in UNAIDS/UNFPA/UNIFEM, 2004: 24

In addition to medical care, governments in rich countries provide social grants to the chronically ill. However, in Africa and the rest of the developing world, government assistance in this area, as in other areas, is extremely limited or unavailable. South Africa is one of the very few African countries that assist certain chronically ill individuals, including PWA, with disability grants. This, however, as most studies show, is often difficult to access. For example, a case study of Mount Frere, South Africa, *Social security transfers, poverty and chronic illness in the Eastern Cape*, aimed at providing an in-depth understanding of social security grants and their relationship to families coping with chronic illness and death, shows how limited this coping resource is. The researchers found that a large number of the chronically ill and entitled to a disability grant were not receiving one, because “the administrative infrastructure for the existing grant system is cumbersome, and under resourced both in financial and human capital” (Sogaula *et al.*, 2002: 55). Another reason is that the majority of the South African poor and chronically ill live in rural, inaccessible areas, which has a dramatic effect on their ability to engage with government services or to be reached by such services (ibid.: 22).

3.4.4 Non-governmental organisations as support systems

Non-governmental organizations (NGOs) play a crucial role in the lives of some chronically ill individuals, especially people living with AIDS. The AIDS epidemic has occasioned the founding of much needed NGOs, particularly in poor and hard-hit regions. These range from relatively well-funded international NGOs, such as the International Community of Women Living with HIV/AIDS (ICW), which was founded in response to the desperate lack of support, information and services available to women living with

HIV worldwide in the early 1990s, to Community-Based Organisations (CBOs) such as The AIDS Support Organisation (TASO) founded in the late 1980s by Ugandans infected and affected by AIDS to offer support, counselling and medical services to PWA. A study by Russel and Schneider (2000) *A rapid appraisal of community-based HIV/AIDS care and support programs in South Africa,* shows that CBOs, despite limited resources, benefit affected households as well as the health service. This is because community-based care:

- Reduces the incidence of hospitalizations and the length of hospital stay.
- Reduces the burden on the primary care system as a result of increased education and awareness about minor illnesses, nutrition and general wellness advice.
- Provides increased support to family members through education, information, counselling and caring for the sick family member. As families better learn to manage the disease, it may free them to attend other obligations.
- Reduces costs to the family (such as hospital fees, transport costs to the hospital, and time spent visiting a sick family member in the hospital), because the patient is maintained at home.
- Promotes awareness of HIV/AIDS leading to acceptance and risk behaviour reduction/prevention.
- Decreases isolation of the family and PWA, by increasing the available support network, and increasing awareness of and access to other community-based services.
- Increases the possibility of drug compliance by providing education and awareness to family and patient, as well as monitoring by health care worker.
- In cases where links between hospital and home exist, allows the hospital to better monitor patients' condition.

Russel & Schneider, 2000: 7

3.5 Concluding comments

In this chapter the aim has been to show the disruptive effects of chronic illness on social relationships and the self. Using the concepts of 'biographical disruption'

(Bury, 1982) and ‘loss of self’ (Charmaz, 1983), which were originally applied to the relatively well-to-do individuals in Western communities, I have attempted to show that such concepts may be useful in understanding the experience of chronic illness among non-Westerners, especially those living in poverty. The studies cited in this review demonstrate that the deplorable living conditions exacerbate the suffering for the chronically ill and poor, but at the same time cushion the existential or ontological assault on selfhood brought on by a chronic illness. It is for this reason that many individuals on the margins of society, especially in rural sub-Saharan Africa, define poverty as their primary concern above all others, including the risk or reality of HIV (Wallace, 2004 in ICW, 2004: 2). How, then, does one tease out ‘biographical disruption’ that results from chronic illness among the chronically poor? This present study is another attempt at hearing gasping individuals, specifically women, infected and affected by AIDS, whose voices are often drowned in poverty.

CHAPTER 4

LIFE STORY RESEARCH FROM A SOCIOLOGICAL PERSPECTIVE

4.1 Introduction

An important aim of this study is to show how the AIDS narratives of the two infected women go beyond the illness experience and encompass other narratives. The same applies to their mothers, a daughter and a grandmother. Included are themes on emotional experiences, past and present socio-economic conditions, socio-political marginalisation and patriarchal domination. To better understand the relationship between different narratives and between the women's stories, the study is conducted within the phenomenological perspective, using the life story research design. The methodological implication of the phenomenological focus on lived experience is that an individual's interpretation of an experience is an essential part of the experience itself (Patton, 1990: 71). Furthermore, a phenomenological focus might help us to have an inside understanding of the women's HIV/AIDS narrative in relation to their lifeworld. An important point is that biographical recounting is not simply a collection of past and present life experiences. Instead, it crucially involves the relations among different narratives within particular social contexts, such as the two sets of three generations of women in this study (Bertaux, 2003: 40; Linde, 1993: 25).

The life story interview is a "method of gathering information on the subjective essence of one person's entire life" (Atkinson, 1998: 3). I use the life story interview as the primary data collection technique. I begin, therefore, with a look at the ontological, epistemological and methodological issues underpinning life story research, before describing the data collection, transcribing and interpretation processes, as well as my role as the main "research instrument". Included in this chapter are narratives of the women in this study. These serve to illustrate some methodological issues and limitations in qualitative research, specifically those found in in-depth interviewing.

4.2 The meaning of life story or biographical research

Life story or biographical research is one of the qualitative study methods. It is a perspective which originated as part of a countermovement to the positivist tradition (quantitative paradigm). The basic ontological assumption in the qualitative paradigm is that reality is subjective, multiple, constructed and contextual (Creswell, 1994: 4). Epistemologically, qualitative researchers interact with those being studied, and take into account the "situational constraints that shape inquiry" (Denzin & Lincoln, 2003: 13). This includes the recognition of the value-laden nature of the research interaction and the researcher's biases, as well as those of the study participants (Creswell, 1994: 6). The focus, for qualitative researchers, is on: the entire process of a study rather than on its outcome; the meaning participants make of their life experiences; the researchers' role as primary instruments for data collection and analysis; the inductive nature of the research process; and understanding participants in their natural environment (Gubrium & Holstein, 1997: 3-16). Thus, "qualitative research engages with the complexity of analysing human action in terms of meanings" (Ezzy, 2002: 29). In opposition to these assumptions, quantitative researchers (traditional positivists) see social reality as objective, something to be studied "from within a value-free framework" (Denzin & Lincoln, 2003: 13).

A life story study is a "fairly complete narrative of an individual's entire experience of life as a whole, highlighting the most important aspects" (Atkinson, 2002: 126). The interview is thus structured to draw out narratives that form an important part of the life story. This includes various related narratives (for example on childhood memory) "as well as explanations and other forms of reflection on and reworking of a narrative" (Linde, 1993: 52). The facts of early years provide a basis for recounting a coherent trajectory of experiences during a life story study (Holstein & Gubrium, 2003: 156-59). A childhood memory, to continue with this example, "contains a large enough number of narratives and their relations to permit us to study the creation of coherence" (Linde, 1993: 52). A life story interview thus enables a researcher to "see and identify threads and links that connect one part of a person's life to another, that connect childhood to adulthood" (Atkinson, 2002: 126). In addition, it reveals the connections between the person and others, such as family members.

The social context, for example a family, is the ultimate "object of the sociologist's intellectual focus and obsession" (Bertaux, 2003: 40). Questions such as: "what makes personal narratives not just the narratives of individuals? And can we learn anything from exploring how they interact with more theoretical stories about social life?" (Finnegan, 1998 in Roberts, 2002: 128), underpin biographical studies in sociology. In addition, "personal narratives reveal the frameworks of meaning through which individuals locate themselves in the world and make sense of their lives" (The Personal Narratives Group, 1989: 22)**.** Thus using a biographical approach to understanding human concerns makes sense in that "its methodology transcends the barriers of self/society as well as those of the past/present/future" (Miller, 2000 in Jones, 2003: 60). Bertaux (2003: 41) sums up a sociological approach to a life story study:

> Although life stories are undoubtedly subjective productions, they can be used as stepping stones to the construction of sociological descriptions and interpretations that come as close to objective sociological knowledge as is humanly possible. Moreover, life stories allow us to reintroduce into social research the dimension of time and the multiple temporalities of activities.

Qualitative researchers recognise and acknowledge challenges, such as subjectivity and its complexities, inherent in their studies when conducting life story research. A starting point in dealing with such issues may be the acknowledgement that "the subject and the subjective are integral features of social life, and … the researcher is a subject in his or her own right, present in the same world as those studied" (Gubrium & Holstein, 1997: 12). Therefore, a world comprised of meanings, interpretations, feelings, talk, and interaction must be scrutinized on its own terms (ibid.: 13). The rest of this chapter deals with some of the methodological issues that highlight a "theoretical sensitivity to the ways that experience is understood and represented by social researchers themselves" (ibid.: vii). I start with a look at in-depth interviewing, which is the primary method of data collection in this study.

4.2.1 In-depth interviewing

The qualitative in-depth or long interview seeks, through questioning, to obtain knowledge of the interviewee's world. A major aim of this type of interviewing is "to explore the contextual boundaries of the experience or perception, to uncover what is usually hidden from ordinary view or reflection" (Johnson, 2002: 106-107). It is a research method that gives a privileged access to our basic experience of the lived world (Kvale, 1996: 54). This type of interview usually has a pre-set theme, but the interviewer and the interviewee are free to respond and explore whatever issues they identify as relevant to the research question or that has meaning to the interviewee (Holstein & Gubrium, 2003: 3-29). Qualitative interviewing is usually concerned with the inside story that can only be told adequately through the deployment of flexible questions (Kvale, 1996: 3-14). Flexibility during interviews allows for the accommodation of the participant's story even if it deviates from the study agenda.

The discussion in the above paragraph raises a methodological issue in in-depth interviewing, namely whether interview responses are to be treated as giving direct access to experience or as actively constructed narratives (Gubrium & Holstein, 1995: 4). Since the epistemology of a qualitative interview is more constructionist than positivist (Warren, 2002: 83), a suggested argument would be that interview responses are actively constructed narratives. These constructions are nonetheless to be treated as 'real' to the participants, because the aim is to understand the meaning attached to the recalled life experiences. Such understanding cannot be gained from surveys or questionnaires that leave no room for individual experiential nuances (Platt, 2002: 51). Interview participants are seen as meaning makers, and not as "passive vessels of answers for experiential questions put to them by interviewers" (Gubrium & Holstein, 2002: 13).

In addition, an in-depth interview is seen as a conversation which has a structure and a purpose where the outcome is a co-production of the interviewer and the interviewee (Gubrium & Holstein, 2002: 12-17; Kvale, 1996: 6). The aim of my study is to obtain a coherent picture of the women's life stories and the AIDS narratives through the interactive process of in-depth interviewing. Armed with this knowledge, I approached the women as active storytellers of their past and present experiences. I did not perceive them as "passive vessels of answers" to my questions, nor did I see them as "repositories of facts, feelings, and the related particulars of experience" (Gubrium & Holstein, 2002: 13). Like other qualitative interviewers, I was sensitive to their power and control over their life stories. How they accessed and made sense of events and experiences in their pasts, and how they related them to their current situations (Mishler, 1999 in Riessman, 2003: 341). Even though the interviewer seems to be the 'person in-charge' during the interview session (Kvale, 1996: 20), the interviewee ultimately has the power to veto what gets told and how it is told, as the following interview excerpt with one of the grandmothers in this study demonstrates:

> **Interviewer:** Are your two daughters who are also HIV+ Lulama's immediate siblings [Lulama is a study participant]?
>
> **Nonceba:** I had a son after Lulama who was stabbed to death. Then after him, it is my two sons and then the two daughters. One of them stays with us in the outside room and the other one stays in Extension Eight.

In the above illustration, the grandmother chooses to include her sons in response to an inquiry on her daughters. Based on this response, one can infer that to this grandmother, all the children need to be included, especially when talking about their birth order. She is not restricted or bound by the study focus area – women infected and affected by HIV/AIDS. In the following exchange, she again shows how a respondent can qualify or change a topic at will:

> **Interviewer:** How is your relationship with your daughters now, and when they were young?
>
> **Nonceba:** First, before I answer this question let me say something more about Lulama. Ever since her injury at the farm, she has been suffering from severe headaches. These headaches are worsened by the smell of food, so it is very difficult to know what to prepare for her. She only likes to eat things that don't have strong aromas, such as mealie porridge or pap. The other two daughters were good as young girls, but now they are very troublesome as they drink a lot.

Again, the question is very specific and yet she chooses to elaborate on a point which may seem as an incoherent account or a digression to the interviewer. For her, the above response is a qualifier to an earlier interview point about her relationship with Lulama. This echoes Riessman's (2003: 331) observation that "it is a common experience for investigators to craft interview questions carefully only to have participants respond with lengthy accounts, long stories that appear on the surface to have little to do with the questions". Riessman (2003) in one of her studies on divorce noted that participants tended to digress from seemingly straightforward questions. She found, like I did, that "the participants were resisting our efforts to fragment their experiences into thematic (codable) categories – our attempts, in effect, to control meaning" (Riessman, 2003: 331).

Despite the above alleged digressions and the participants' resistance to our efforts to contain their lengthy narratives, they are nonetheless quite aware of the "rules of conversational storytelling" (Riessman, 2003: 331). To continue with the grandmother, she is aware of the interview/conversational rules. She states that she would like to say something before responding to the question, "first before I answer this question let me say something more about Lulama" (Nonceba, 77 years old, Grahamstown). This signals to me that what she is about to say will not be directly related to the question at hand, but is meaningful and adds coherence to her story. This illustration highlights the difference between the traditional or standard practice of research interviewing on the one side and the life world of naturally occurring conversation and social interaction on the other (Mishler 1996 in Riessman 2003: 331). It is for this reason that feminist and narrative researchers give voice to the researched by respecting the participant's way of organising meaning in her/his life (see Gluck & Patai, 1991; Josselson & Lieblich, 1995). In so doing, these researchers 'welcome' and accommodate narratives that have no direct bearing on their research topic. These 'digressive' narratives do not fragment participants' stories. Instead, such narratives help in presenting holistic accounts of the particular topic from the participant's perspective (ibid.).

The above discussion shows the complexities inherent in in-depth interviewing, and an attempt to deal with and acknowledge these intricate matters (see Gubrium & Holstein, 2002; Holstein & Gubrium, 2003; Riessman, 2003). I will continue to deal with some of these complexities throughout this chapter.

4.2.2 Memory and emotions in biographical narratives

In his book *Memory and emotion,* McGaugh (2003: 2) suggests that memory "is our most important possession, our most critical capacity. We are, after all, our memories". This echoes Norman Denzin's assertion on emotion (see 2.2.1) that "people are their emotion". Memory provides us with a biographical record and enables us to understand and react appropriately to changing and unfolding experiences. For McGaugh, "memory is the glue of our personal existence. We live our lives moment by moment" (ibid.). Therefore, whether implicit or explicit our memories connect the past to the present and allow us to form expectations of the future. Memories are our most important assets, and without them life as we know it would be impossible. Of all memories, those of emotionally arousing events tend to be the best remembered (McGaugh, 2003: preface). This emotionality in memory, to repeat the earlier assertions, shape and inform concepts of self, 'we are our emotions and memories'.

In biographical research, dealing with recollections of past experiences, that is memories, means that we are one step removed from the lives we wish to understand. This is due to the "countless distortions and falsifications to which recollections are subject" (Freeman, 1993: 8). We remember selectively, and sometimes "confer meanings on experience that did not possess these meanings at the time of their occurrence" (ibid.). Furthermore, we weave these "meanings into a whole pattern, a narrative, perhaps with a plot, designed to make sense of the fabric of the past" (ibid.). Memory is not simply about recounting the past but also about making sense of the past. It is an interpretive act in which the self is better understood. This is an ongoing enterprise, as individuals re-interpret the meaning and significance of past experience (ibid.: 29) and merge these interpretations with current experiences. As the women in this study did during the interview process, most of their recalled experiences were interpreted based on their present lifeworlds.

4.3 Finding the women

Based on the study topic – 'the intergenerational experiences of women affected by HIV/AIDS', I wrongly assumed that finding such women would be relatively easy. This assumption was informed by the statistical evidence and common knowledge understanding of HIV/AIDS prevalence in South Africa (see 1.1). Criterion sampling was utilised for the identification of two sets of three generations of women – mother, daughter (living with AIDS) and granddaughter. Criterion sampling or purposeful selection is when all participants experience the phenomenon being studied (Creswell, 1998: 118). Gaining access to this group of women proved to be challenging. I initially approached local municipal clinics and the hospital as places from where I would draw the study participants. There were bureaucratic barriers such as writing a prerequisite proposal for the intended study to the provisional management at Bhisho (Head Office for the Eastern Cape Province's Department of Health). Only when Bhisho had given sanction would the local authorities give me access to the target group. According to the individuals I spoke to at the local hospital, this procedure is intended to protect HIV positive individuals from being exploited. After one month of no response from Bhisho, I decided to revert to HIV/AIDS NGOs as sources for possible participants.

I had initially refrained from seeking study participants from local HIV/AIDS organisations. This was due to a major concern I had while working with two women in 2004 for an Honours research project on women living with AIDS. The two participants, who were purposefully selected from the Raphael AIDS Centre in Grahamstown, focused their stories on what I took to be 'conventional' HIV/AIDS narratives and not personal life experiences. Even when they talked about life experiences outside their HIV/AIDS involvement, such experiences were still told through the highly politicised HIV jargon. It is for this reason that I cautiously agreed to be introduced to the manager of another local AIDS organisation by a church elder in my church. On this particular Sunday, the manager of the Grahamstown Health Development Forum (GHDF), Mrs Monica Mcuba, and a group of volunteers had come to thank the church members for their financial and material donations (the Trinity Presbyterian Church in Grahamstown is a major supporter of this organisation). The manager informed me that the majority of the homes on the list of the GHDF are female-headed. This reason and the fact that household members do not receive extensive AIDS counselling, helped in my decision to draw the study participants from the list of female-headed households on the GHDF list.

I explained the proposed target group to the manager, who assured me that finding such women would be relatively easy. However, this was easier said than done, as it took her nearly three weeks to find willing participants who matched the study profile – a mother, an HIV positive daughter and a granddaughter, older than twelve years, all living in the same house. The first two households that agreed to be interviewed had to be abandoned as both daughters died of AIDS-related illnesses within days of each other. After these sad occurrences, I told her to look for HIV positive women who were not in the final stages of AIDS, or those who were on treatment. The difficulty in finding the right profile of women, namely mother, daughter with AIDS and teenaged granddaughter, necessitated an inclusion of three generations of women not specifically meeting the criterion of participants. In the second household, unlike the first, it is the granddaughter who is HIV positive. In addition, there is a grandson with full blown AIDS living in this household, who was unintentionally drawn into the study (see Appendix V for his abridged biography).

As a non-Xhosa speaker, I needed a translator for the interviews. Mrs Mcuba graciously accepted my request to be involved in the study as a translator.

4.4 Conducting the interviews

In-depth interviewing was the main technique used in collecting the life story narratives of the women in this study. This, as explained above, was the ideal research method to give me and others a deeper understanding of the women’s lifeworlds. An interview schedule was prepared, guided by the in-depth interviewing tenets, the research needs and the themes from the literature review. The aim was to establish a general direction for the conversation during the interview, which would fit the broader aims of the study. The interviewing guide (see Appendix I) had three major parts: the opening, the body and the closing. The opening dealt with issues such as common everyday etiquette that is expected between individuals meeting for the first time. For me, this was made easier because the translator, Mrs Monica Mcuba (more about her later), is known by the women in the study. Another major factor that helped in establishing rapport, fairly quickly, is that both the translator and I are women. This common womanhood may have been perceived as a basis for mutual respect and intimate self-disclosure on the part of the women.

During the introductory visit I explained the aims of the study, the duration of the interviews and the need for subsequent interviews. Importantly, I obtained verbal consent from the women and explained ethical issues such as confidentiality through the use of pseudonyms in the thesis write-up. I explained that interviews were going to be tape recorded, and sought permission for the recording. I also explained that the study was for academic purposes only, and as such no material benefits for the women would arise from it.

The body of the interview schedule contained questions which were meant to elicit personal information, as well as inter-familial details. This included biographical, migratory, and inter-personal details, as well as HIV/AIDS narratives. These guiding questions still allowed for probing and follow-up questions as the need arose during the interview sessions. As noted earlier, life story (in-depth) interviewing is flexible, and as Atkinson (2002: 130) suggests, “the key to getting the best interview is for the interviewer to be flexible and able to adapt to specific circumstances”. For example, one woman in my study unwittingly ‘steered’ the interview away from these ‘pre-set’ biographical questions by introducing a topic – her mother’s pension grant (see 4.5.2 and 6.1.5). I accommodated her by exploring this topic further and in detail with her and the other family members (mother, daughter, son and nephew).

The third and final part of the interview schedule – the closing – deals with the protocol of ending an interview. This includes ending the interview session in a brief, but not abrupt manner and thanking the women for their time. During this part I also notified them of follow-up interviews to clarify issues and gave them provisional dates for subsequent interviews.

4.5 A field interpretation

Most qualitative studies begin the analysis/interpretation of the data during the data collection process, whether this is made explicit or not. The integration of data collection and data analysis is practiced by a number of qualitative research traditions such as ethnography, participatory action research and grounded theory (Ezzy, 2002: 60-61). In my case, data interpretation occurred as a matter of course, as I was forced to ask for clarification of certain narratives a number of times during the interview and the translation/transcribing process. This was because I am a non-Xhosa speaker and I used translators in the interviewing and transcribing processes. Meaning had to be re-worked and re-negotiated between the participants and the translator, between the translator and myself, as well as between the second translator and myself throughout the transcribing process. Ezzy (2002: 64) has described a number of practical techniques that can be utilised as tools for integrating interpretation/analysis and collection during the qualitative interviewing process:

- Team meetings and peer debriefing.
- Checking interpretations with participants.
- Transcribing, reading and coding early data.
- Writing journals and memos.

I use the above techniques to show how interpretation and collection of data was concurrently done in my study. Like most qualitative researchers, I was unaware of the significance of these techniques during the interviewing and transcribing processes. For example, the long and tedious process of transcribing interviews was doubled in my case, as I used other translators (see 4.5.1 and 4.5.3). The positive effect was fully appreciated during the interpretation of the interview transcripts. This proved to be considerably easier because of my earlier active immersion in the women’s narratives. I expand on this in the following four sections.

4.5.1 Team meetings and debriefing

Debriefing meetings were held between Professor Coetzee (my supervisor) and me. In these meetings, I benefited from his ‘objective’ look at the verbal updates of the interviewing process. To a certain extent, I experienced what Anselm L. Strauss, an accomplished collaborative qualitative researcher, identifies as four main benefits from team meetings. First, he notes that discussing the data of the research stimulates ideas about its meaning and significance. Second, some issues that arise during the discussion are elaborated upon and developed and they provide additional depth of complexity and quality of analysis to the research. Third, the issues raised may lead to team members choosing to follow up research issues through new data collection, the addition of questions to the research schedule, or reviewing data collected earlier for an analysis of the issues raised. Lastly, team discussions may inform the writing up of the project, particularly if they are transcribed (Ezzy, 2002: 65-66).

In addition to the meetings with my supervisor, I held regular meetings with Mrs Monica Mcuba, one of the translators. She is the manager of the Grahamstown Health Development Forum (GHDF), an NGO that provides lay counselling and food parcels to individuals living with AIDS and their families. In the initial meeting I explained to her the aims and goals of the study, including the life-story interview technique. In subsequent meetings l informed her on the follow-up questions and emerging themes from previously transcribed interviews, which I wished to focus on. This brief allowed for spontaneous exchanges between her and the women during the interviews. Furthermore, she felt empowered to probe or ask qualifying and clarifying questions during the interviewee’s long narratives.

Even though the translator is not an academic and was unable to give me peer reviews and suggestions, she nonetheless proved to be a rich source of background information on all the study participants. Her life trajectory is in some ways similar to those of the participants. She, like the first two generations (mothers and daughters) in the study, was born on a white-owned farm and then moved to Grahamstown. She stays in the township, albeit in a better area. She is a lay-counsellor and her experience in this line of work has equipped her with interpersonal skills that proved invaluable for the interviews. In addition, she already has a working relationship with both households included in my study, as they are on the GHDF list that are provided with counselling and food parcels.

The translator's prior relationship with the women greatly helped me to establish and maintain rapport with the participants. Although this was mainly beneficial to the study, there was a downside to it. Nearly all the participants viewed me as an NGO/social worker. This inevitably raised 'false' beneficial expectations of the study's outcome. This is illustrated in the following excerpt. A grandmother, who is constantly left alone by her daughter and grandchildren, explicitly refers to the translator and me as 'the people from the government':

> When my daughter comes I am going to tell her that the people from the government came and that I told them everything, the whole truth – 'how you leave me alone; that you went out last night and never came back; that you stay with a boyfriend as if you are married'. I was not brought this way. We did not sleep with our boyfriends before we got married to them. I do not like what my child is doing.
>
> Nomaindia, 83 years old, Grahamstown

Similarly, her contemporary tries to bring to our attention the poor condition of her house:

> Oh, please try and sort out this issue with the house so that we can live in a proper house. Just take a peek at my room, just a peek. Yewh…no, no, no. We have been registering in all these places where houses have been made available, because we have not gotten anything. Not at all. Not even one of the children has been successful in getting a house, because they can't all be staying at home with their own children. But you wouldn't say that because other people own about 3 houses and yet they don't even want to give one to these children. They have brought more hardship for us. They keep on saying that they are going to provide for us

> but we end up using our money from the grant to repair these things. That's why we don't have anything to eat, it's because we are trying to repair this room. As you can see this gravel outside, someone said he was going to help us repair this room. That cost money. And yet this government keeps on saying that we must vote for it. My question is must we vote for shacks?
>
> Nonceba, 77 years old, Grahamstown

As evidenced in the above utterances, I am seen as a 'government official' with power to effect change. This, as earlier pointed out, had an effect on how the life experiences were told – the focus was on the problems they experience, whether personal or interpersonal. It can be argued that the women's 'narratives of suffering' are not imagined, but are real to them, and I evidenced some. Notwithstanding this argument, I believe that the women would have balanced the 'suffering' and other narratives had they perceived me differently. To counter this weakness, I deliberately asked the women questions on 'happy childhood memories'. In response to this question, a daughter living with full blown AIDS, said:

> It was nice when I was growing up. There were parties we used to go to and we would dance and dance at those parties. It was fun then and we didn't have… If you had a disagreement with someone, you would disagree and it would end there immediately after that. It was nice.
>
> Lulama, 48 years old, Grahamstown

In addition to the meetings with Professor Coetzee and with Mrs Mcuba, I held debriefing meetings with the second translator of the recorded interviews. This interaction is discussed fully in section 4.5.3 below.

4.5.2 Checking interpretations with participants

Feminist and participatory researchers propose that research participants be included in all aspects of the research process (e.g. Gluck & Patai, 1991; Reinharz & Chase, 2002). These researchers have pointed out the important political implications this has on the research process. Furthermore, checking interpretations with participants provides "a mechanism for developing dialogue with the research participant that is at the heart of the qualitative research process" (Ezzy, 2002: 68). For me, checking of certain interpretations was integrated with data collection as follow-up questions that were intended to clarify or confirm specific issues. This is illustrated in the following excerpt:

Interviewer: When we came last time we found that your mother was going to be left alone. Mbulelo was home, but he was going to go away later that day, and your mother decided to go and stay at a relative’s house nearby. How do you explain this?

Ntombi: I am very upset with the way my mother has given Sipho my son the responsibility of managing her money, when I am the one who is expected to look after her. I would rather be away from this house than see my mother starving as there is usually no food in the house [spoken with a lot of emotion].

Interviewer: How does your mother feel about this?

Ntombi: I have always asked my mother to talk to Sipho about his mismanagement of the money, but she never confronts him. I have indicated to her that her keeping quiet on this matter gives Sipho the impression that I just want to control the money and he thinks that since the owner of the money does not complain then everything is okay. I need my mother’s support on this issue. He brings small amounts of groceries and he never gives us any money.

Regarding the above extract, I needed to confirm my assumption that the daughter and the grandchildren are upset with the grandmother for letting a grandson, who does not reside in the home, control and manage her old age social grant. This information was communicated to us during a solo interview with the grandmother, illustrated in the following excerpt:

Interviewer: Do you have control over the pension money? Do you go with someone to collect it?

Nomaindia: My grandson collects it for me.

Interviewer: Where is he?

Nomaindia: He has his own house; he does not stay here with us. He does the banking and collecting of my pension.

Interviewer: How does your daughter and the other two grandchildren feel about him managing the money when he doesn’t even stay in the house?

Nomaindia: He also handles my debts and I know how much is owed to who and what the change is [this is not entirely true, because at the end of the interview when we gave an amount of R50 as a token of appreciation, she did not know how much it was. Her sight is bad and I suspect that she can not count properly either. Monica and I concluded that the grandson is using some of the pension money, without the knowledge of the grandmother].

Interviewer: Okay, how does your daughter and grandchildren feel about him handling the money?

Nomaindia: Before, he started managing the money, Mbulelo [a grandson who stays with her] used to handle it, but there were problems. He used to crook me. Then I said no more [emphatically spoken]. After this we decided that Mbulelo should stop handling the pension. We needed somebody within the family to take over. This is why this grandson of mine who does not stay with us handles the money now. Mbulelo used to lie about what he did with the money.

Interviewer: Do you go with someone to collect the pension?

Nomaindia: My legs give me problems and I can’t walk properly. And I can’t afford to take a taxi as there is no money when it is time to go. This is why I have asked my grandson to go to the pension on my behalf as he is stronger.

In addition to confirming my assumptions on the daughter’s and the grandchildren’s unhappiness, the above extracts act as checks for the mother’s and granddaughter’s stories on the subject.

4.5.3 Transcribing and interpreting early data

The initial interviews were transcribed by a Xhosa-speaking Bachelor of Social Sciences (Honours) graduate, who, at the time of transcribing, was employed as a transcriber at the Centre for AIDS Development, Research and Evaluation (CADRE) at Rhodes University. This was a deliberate choice, because I had noticed that the translator was rather brief in her translation of the narratives during the interviews. I had no way of knowing whether what she chose to leave out were repetitions or whether she simply deemed it as irrelevant information. The transcriber confirmed my observations and suggested that I use another translator for subsequent transcribing, as she was unable to transcribe all the interviews. She, however, noted that the translator had captured the essence of what the interviewees were saying as precisely as she could, even though she left out certain specifics. The translator privileged the meaning of the whole narrative above the specific details. This is in line with life story research and qualitative methodology as a whole. This perspective has its focus on the subjective meanings and interpretations that 'social actors' whose life stories are studied attach to their recalled experiences and actions. However, subjective meaning carried in the specifics is lost and may alter the meaning of the translated narrative. This may adversely affect interview narratives in studies dealing with specific topics. In a life story interview, however, loss of meaning is minimised as the data is interpreted and presented as a whole, not as a particular topic.

On recommendation of the above transcriber, I sought a second translator during the transcribing process of subsequent interviews. The first transcriber (and translator) was unable to continue transcribing as she got a job in Johannesburg, South Africa. The second translator was also a first language Xhosa speaker, in her second year, studying towards a Bachelor of Social Science degree at Rhodes University. Transcribing was preceded by a brief on background information of the women, recorded narratives, my personal observations and impressions in the field. She, like the above transcriber, checked for omissions or changed meaning in the recorded interviews, which may have occurred during the translation process. As tedious as the transcribing was, the process facilitated an immersion in the women's stories, and served as a preliminary form of narrative interpretation. In addition, it highlighted the ethical issues related to qualitative interviewing and my own personal ethical dilemmas (see 4.6). During the transcribing process, the translator asked questions that provided me an opportunity to explore certain themes and narratives in subsequent interviews.

4.5.4 Journals and memos

As other qualitative researchers have experienced, writing about my impressions and observations in the field enhanced my emerging understanding of the women's life stories (Ezzy, 2002:71-74; Silverman, 2005: 249-53). For example, writing about the physical condition of the two houses helped me in contextualising the interpretation of the interviews (see Appendices III and IV). My inferential notes on the two households enabled me to understand better the women's non-verbalised "gritty details of biography"

(Farmer, 1997: 262), discussed in Chapters 5 and 6. This field experience echoes Hammersley and Atkinson's (1983 in Silverman, 2005: 251-2) comment:

> The construction of such notes … constitutes precisely the sort of internal dialogue, or thinking aloud, that is the essence of reflexive ethnography… Rather than coming to take one's understanding on trust, one is forced to question *what* one knows, *how* such knowledge has been acquired, the *degree of certainty* of such knowledge, and what further lines of inquiry are implied [emphasis in original quote].

4.6 Interpreting the narratives

As I have already noted, the interpretation of the women's narratives was done concurrently with the data collection process. As a qualitative researcher studying meaning, it was imperative that I "worked to understand the situated nature of participants' interpretations and meanings" (Ezzy, 2002: 81). This called for a repeated immersion in the women's life stories through the observations and the reading/interpreting of the interview transcripts during data collection. This immersion allowed me to identify and explore themes emerging from the data. It also enhanced my understanding of the women's life stories. When analysing data, I interpreted the narratives thematically, that is, interpreting common narratives from the interview transcripts. While I had a general topic, 'the impact of HIV/AIDS on three generations of women', the themes that I explored went beyond the AIDS narratives to include other lived experiences. For example, section 5.4 *A 'curse from God': experience of life-long suffering'*, as the title suggests, is about life-long suffering that precedes and supersedes the women's HIV/AIDS narratives.

4.7 Reflections on my role as a researcher

A major challenge I faced in the interview process was language. I am a non-Xhosa speaker and only one of the participants speaks or has an adequate understanding of English. This language limitation constrained the phenomenological demands for both the participants and myself, that is, to seek to discover the world as it is experienced by those involved in it. Some of the nuanced meanings the women attached to their recalled experiences were lost during the translation process. How did my presence, as a researcher with obvious material and social advantages (such as driving a car and studying at a privileged university), impact on the women's responses to the questions? This question has significant implications for my understanding and interpretation of their narratives. As I have already noted, both grandmothers saw me as a 'social worker' or some government agent with power to redress their dire needs. This meant that these two women's responses were shaped to highlight what they perceive as problem areas. A typical example is when one grandmother explicitly asked me to tell 'them' about the condition of her house, "Oh, please try and sort out this issue with the house so that we can live in a proper house". Like other qualitative researchers, this left me feeling as if I was just "holidaying on people's misery" (McRobbie 1982 in Letherby, 2000: 101). It is distressing to know that I encouraged the women to talk about their difficult experiences, only to then abandon them to continue their lives as usual. How then do I 'bracket' these concerns and present a balanced interpretation of their stories? By balanced, I mean a deliberate focus on the study topic and leaving out peripheral themes, such as conditions of the houses.

4.8 Concluding comments

The discussion in this chapter centred on qualitative methodology and the debates surrounding this form of social inquiry. Specifically, I focused on the ontological and epistemological assumptions underlying life story or biographical research. This deals with the issues of social reality being perceived as subjective, multiple, socially constructed and highly contextual. In the case of this study, one may ask: How do the women in this study make sense of their lived experience? To what extent were the interview questions shaping the recollection of particular experiences? From these methodological issues, I then described the study process, to show how data was created by the participants and me, as well as by the three translators. The use of interview transcripts highlights the complex interplay between the women's recollections and the study questions. The women were not bound by the interview questions, but by what they deemed meaningful to their life stories and selfhood. In contrast, I was trying to "manage" what was said by asking questions that corresponded with my overall study topic, namely an intergenerational narrative account of the experience of living with

HIV/AIDS. Finally, I interrogated my role as the main data collecting instrument and the impact that my social position had on the women’s responses to the questions. Would the women have told different life stories if, say, they had only been interviewed by Mrs Mcuba or a Xhosa speaker living in similar conditions? These concerns and many others make qualitative and human inquiry ongoing projects. As the phenomenological and social constructionist discussion in Chapter 2 shows, social reality is a process whereby people continuously create, through their actions and interactions, a shared reality that is experienced as subjectively meaningful. For this reason, then, social research, specifically phenomenological studies, can only hope to uncover the various layers of experience, and the different structures of meaning involved in whatever phenomenon is under study. Significantly, the researcher should as far as possible, ‘bracket’ her/his commonly held knowledge on the study topic.

CHAPTER 5

CHRONIC POVERTY AND HIV/AIDS: AN INTERPRETATION OF THE NARRATIVE

5.1 Introduction

The aim of this study was to understand the impact of HIV/AIDS on three generations of black women living in a single household in abject poverty. This called for a phenomenological exploration of the women's narratives on how they cope with HIV/AIDS and life in general. How do they make sense of their lifeworld in relation to the other women in the household, be it a grandmother, mother, or daughter? This question underpins the interpretation of the interplay between the women's stories as presented in this thesis. The underlying theme in the stories of the women is their life-long suffering due to chronic poverty. This poverty, to repeat a Ugandan proverb, "passes from one generation to another as if the offspring sucks it from the mother's breast" (Group of disabled Ugandan women in CPRC, 2004-05: 3). The interpretation of the women's stories is underpinned by the discussions in previous chapters, especially the ones on emotions and chronic illness. In Chapter 4, I included and interpreted the study transcripts as illustrations of some of the debates in qualitative methodology. Like other qualitative researchers, what I present here is a fraction of what was told and is selectively themed to fit the agenda of the study.

I start with a brief biographical account of each of the six women, which provide the basis for this study. This is presented in chronological order, starting with a grandmother, mother and then a daughter in each of the two households (see Appendices III and IV for an account of my general observation of the two households). Each biographical account enables the reader to better understand and appreciate the interpreted parts of each woman's story as they are discussed in relation to the other. All names have been changed to protect the identities of the women. The first set of grandmother (5.2), mother (5.2.1), and daughter (5.2.2) are the principal participants. They represent the original research design (see section 4.3). This draws out the impact of AIDS on the three generations of women that I seek to highlight and understand. This set of participants was adequately articulate and most of their detailed responses were highly informative and relevant to the study.

5.2 Nonceba, 77 years old

Nonceba (pseudonym) was born on 7th January, 1929 on a small farm near Port Alfred, in the Eastern Cape Province. She was an only child, and her mother died when she was still young. She was brought up by her maternal aunt, who, she claims, treated her like a servant. She has unhappy memories of this period of her life, which are juxtaposed with happy childhood memories. She nostalgically talked about the “good old days” when household necessities such as firewood were free. She contrasted this with the “bad times” of today where everything, even “my nail” is for sale. She nostalgically reminisced that they lacked nothing in terms of life’s necessities. She has never been to school, and does not see this as a limitation in her life. She does not see the point of formal education when one can not use the knowledge acquired in school productively. She got married early, partly to run away from her abusive aunt. She continued to be abused emotionally and physically by her husband from the start of the marriage, until he died. She had eleven children, five of whom died in infancy, and an older son was killed in a car accident. She has five surviving children, three daughters and two sons. Two of her daughters and their children stay with her. All her children were born on the farm. Her family was evicted from the farm when her husband could not work due to ill-health. They moved to Grahamstown, where they squatted in various people’s backyards, before moving to their present home fifteen years ago.

Nonceba’s natural ability for telling a captivating story and her emotively articulated dire lived experiences inspired my selecting her household as primary participants. Despite the pain throughout her life, she has an exuberance about her that draws one into her world through her words. Her litany of woes, which were eloquently and emotionally expressed, include two daughters and a grandchild who are HIV positive, two of them in the full blown AIDS stage. All the three HIV positive progeny live with her, as well as three other grandchildren. Two of these, a daughter and a granddaughter, are participants and their biographies follow.

5.2.1 Lulama, 48 years old

Lulama (pseudonym) was born on 10th October, 1958 on a farm near Port Alfred in the Eastern Cape Province. She is Nonceba's eldest surviving child. Like her mother, she has nostalgic childhood memories, both good and bad. She remembers people being more tolerant and understanding, that "when one had a disagreement, it was usually settled amicably and the friendship/relationship continued". Her education was limited to a few years of primary school. This was due to the long distance between the school and her home. She worked on the same farm as her parents. She suffered a head injury while canning pineapples and did not receive medical treatment, and she continues to suffer from the effects of this accident. Both she and her mother still resent the farmer's indifference when she was injured. She has two daughters and a son. With limited help from her mother, she has always been responsible for her children's upbringing. She tested HIV positive in 1998, after her youngest daughter was diagnosed HIV positive. The child had been sickly since birth. When she was diagnosed, she experienced stigma from the community and some family members. The pain from the AIDS stigma was compounded by her husband's refusal to accept her HIV positive status. This caused her to attempt suicide, by drinking petrol and pills. The stigma has lessened and she now belongs to an AIDS support group. She and her child are on ARV treatment, and they both receive AIDS support grants. The child's father died from an AIDS-related illness. He initially hid his status from her. "He never told me that he was HIV positive. He only told his mother, who later told me". He accepted her condition only when

> he learnt that I was about to start receiving an AIDS grant. He said that he was glad that we were both going to be getting the grants and this would enable us to live comfortably. He was by then receiving a disability grant for his mental illness. He pleaded with me not to disclose my status to people and that I should stop attending the support group at the clinic or to go for HIV medication. However, I ignored him and I am a member of a support group and I am on ARV treatment.

Understandably, Lulama privileges her AIDS-self above her other life experiences. Her presentation of self in this study continuously drew on her HIV/AIDS narrative.

5.2.2 Zintle, 23 years old

Zintle (pseudonym) was born on 7th July, 1983 in Grahamstown. Unlike her mother and grandmother, she has predominantly sad memories of her childhood. She relates this to the segregation policies of apartheid and the impact this had on her. She is still pained at not having been allowed to attend good white schools and of having been seen as "sub-human just because one was Xhosa". Other sad childhood memories relate to her family. There has been massive alcohol abuse in this family, which she continues to experience. She has consciously refrained from drinking alcohol, as the pain it causes far outweighs the 'delights', in her view. She often mediates in the alcohol-related squabbles, which she finds extremely distressing. A rare fond memory of her childhood is of her grandmother telling the family Xhosa fables. She has completed Grade Twelve and wishes to continue studying towards a qualification in social work. Three months after the initial contact with this family, at the concluding interview, we were told that Zintle had got married. I conducted a brief interview to find out what led to this impromptu marriage, as none of them (grandmother, mother and Zintle) had indicated in the previous interview that she was engaged or about to get married (see Appendix II). My concern was why such crucial information had been withheld, as it had implications on the care-giving story. It made me wonder whether what she had said regarding her role as care-giver to her mother and young sister was 'truthful'. I therefore asked her to tell us about the impact of her marriage on her role as care-giver and other aspirations for her family. She said that the speed at which the marriage happened was equally surprising to her and her family. She noted that even though her boyfriend had discussed marrying her, she thought it would be some time in the future. Regarding her care-giving role, she noted that her husband has agreed for her to continue helping her mother and young sister. This is possible as her marital home is very close to her natal home. However, she had to negotiate the care-giving role with her husband's people. This was necessary as Xhosa custom dictates that a newly wed bride does *umsebenzi* (household chores) for her in-laws. Regarding her aspirations of becoming a social worker, she noted that she would love to see this dream come true, but acknowledged that it would be more difficult to realise it given her present circumstances. Her husband works for a dry cleaning company and his income is barely enough to meet their household expenses. When asked if she and her husband took an HIV test before marriage, she confirmed that they had. They are both HIV negative.

5.3 Nomaindia, 83 years old

Nomaindia (pseudonym) was born on 23rd March 1923, on a farm in Manley flats, near Port Alfred, in the Eastern Cape Province. She went to school, but only for a short while (sub-A) as the school was far from the farm. She found “walking such a long distance unbearable” and quit school. She had to move to Grahamstown with the farmer as a domestic worker. However, she went back to the farm to look after her old and frail mother. She, like her contemporary Nonceba, prefers the past to the present. For example, she noted how children were respectful to adults, and compared them to today’s ill-mannered youth. As she said, “I never even contemplated lifting a finger to my mother”, and yet her daughter and grandchildren constantly abuse her, both physically and verbally. She also talked about the abundance of food in her household then. They hardly have enough to eat, let alone to satisfy her ‘granddaughter’s elephant appetite’. Her one dream was to live a good and healthy long life, so that she could look after her mother. This dream was shattered when she got married in Grahamstown because she could not be near her aged mother who still stayed on the farm. She had nothing but good things to say about her husband. She described him as a very quiet and stable man who never drank or laid a finger on her. He was tragically stabbed by a group of youths a few years ago. She has a very pragmatic view of her being the sole provider for her adult child and two grandchildren. She reasons that since there is no one working in her household the onus falls on her to care for the family. She sees her role of provider as being similar to that of her mother’s, and believes that it is only natural for a mother to care for children, no matter what. Even though she is concerned about her HIV positive grandchildren, she knows very little about the seriousness of the disease, because she has yet to experience the devastating impact of full blown AIDS. Her granddaughter was recently tested and is yet to experience the ill-effects of AIDS. However, a grandson is living with AIDS and is on ARV treatment, but he has never been nursed at home. He was admitted to SANTA hospital for a long time, and was at the time of the interviews at home and in relatively good health.

Compared to the eloquent 77 years old Nonceba, Nomaindia is inarticulate, submissive and in very poor health. She is nearly blind, can not walk without aid and she is unable to adequately care for herself. This was evident in her appearance (unwashed body and cloths) each time we conducted interviews in her household. Her geriatric vulnerabilities are worsened by the behaviours of her daughter and grandchildren. In addition to their emotional and physical abuse, they often leave her alone. Her pension grant is also misappropriated by one of the grandsons. As a result there is never enough food or money for other household expenses (e.g. electricity payments).

5.3.1 Ntombi, 46 years old

Ntombi (pseudonym) was born in 1960 in Grahamstown. Other than the occasional stay in Port Elizabeth, she has always lived in Grahamstown. Like the principal participants, Ntombi’s family has also squatted in different places within the Grahamstown informal settlement. She does not really have strong memories of her childhood, only that she was happy and that her mother raised her well. She said that her life has improved now that there is no more apartheid. She went to school and dropped out in standard 4 (grade 6), when she fell pregnant. She got married, had a son and a daughter and later got divorced. She has only done domestic work and has worked for various people. Her relationship with both her children is very strained, especially with her daughter. She has on several occasions called the police or reported her daughter because of the verbal and physical abuse directed at her and her elderly mother. Even though she feels sad about her daughter’s HIV status, she is not overly concerned about her due to her behaviour. At the time of the interview her daughter had run away from home and was staying with friends in a different location. Her relationship with her son is slightly better, as he is less abusive. She, nevertheless, accuses him of squandering her mother’s old age pension grant. She is extremely bitter that her mother has entrusted her son to manage the grant. Her relationship with her mother is very strained as a result, to the point that she leaves her alone for days. She claims that the major reason that causes her to leave her mother alone is that money lenders (‘loan sharks’) go over to demand money they owe. Her family was recently allocated a new government-subsidised house.

Ntombi noted that she is very happy to live in such a home. It has a flush toilet compared to the bucket toilets in previous homes.

5.3.2 Palisa, 21 years old

Palisa (pseudonym) was born in 1985, in Grahamstown. Like her mother and grandmother, she only has rudimentary education – standard 3 (grade 5). She left school because of poverty. The only person responsible for her school needs was her aged grandmother. Both her parents are unemployed and have only held occasional domestic or casual employment. She remembers being well looked after by her grandmother with the little she had. She, like her contemporary Zintle, has always experienced the negative effects of alcoholism in her family. Unlike her peer, she is an alcoholic and abuses her mother and grandmother when under the influence of alcohol. She was diagnosed with HIV in March, 2005. She does not seem overly concerned about her status, as she was counselled and has accepted her status. She said that her mother also encourages her not to think about her status all the time. She is certain that her mother will look after her when she gets ill, even though their relationship is currently strained. She has never worked and is not looking for a job “because there is none to be found”. She is not sorry that being HIV positive has robbed her of the possibility of becoming a mother, as she never desired to have children. Despite these feelings, she did express a wish for a child if her life circumstances changed. She is very angry at her family for all that is happening in her life. She dreams of going back to school, so that she can train to be a nurse. She likes being with friends and sees drinking alcohol as therapy for her awful life condition. She attributed most of the conflict between her and her family to her abusive male cousin. This male cousin was drawn into the study, unwittingly, and his biographical account is included in Appendix V.

5.4 A ‘curse from God’: experience of life-long suffering

The experience of chronic poverty/suffering is a core theme in the women’s life stories. In my observation and according to the women’s narratives, it supersedes the suffering brought on by AIDS, in both households. All the six women talked about the life-long, sometimes unimaginable, experiences of suffering, which inevitably is passed on to succeeding generations. For one grandmother, it is enough to lead her to believe that God has cursed her. She made this statement on a number of occasions, when narrating various difficult episodes of her life:

> Sometimes I feel like God has cursed me. Because it doesn't seem that other people are as angry or hurt as I am and they don't have bad things happening to them, like I do. It seems as if I am the only one having all the bad things happening in her life. It is like God has something against me. I am afraid to speak it out because I don't want her to hear me say that [she is referring to her daughter with AIDS, who was in the room when this interview was conducted. The mother was afraid that it would upset her daughter and that it may seem as if she was complaining about her]. How long have I been suffering? Since I was a child I was suffering up until now. Now that I should be resting, yet I am still suffering.
>
> Nonceba, 77 years old, Grahamstown

During a subsequent interview, when her daughter was not present, she felt free to express the anguish that she experiences in her care-giving role. When asked how she feels about nursing her daughter, instead of the daughter taking care of her, she said:

> Oh, my God, my child, it really hurts me. When I am nursing her, which happens often, it reminds me of all the other children that I have lost [died]. I cry out to God and ask him why he is punishing me and when is he going to let me off. I feel like I am cursed [narrated in a very emotional voice]. Sometimes I feel like not even Satan can be this cruel to a person.
>
> Nonceba, 77 years old, Grahamstown

What does this woman's interpretation of her chronic difficulties tell us? By viewing her past and present circumstances as a 'curse from God' the grandmother is attempting to make sense of her inexplicable suffering. As she laments "not even Satan can be this cruel to a person" (Nonceba, 77 years old). This cry articulates a desire for a divine reprieve in her stream of calamities, "I cry out to God and ask him why he is punishing me and when is he going to let me off" (Nonceba, 77 years old). This ambivalent belief that God has both the power to 'curse' and 'let me off' demonstrates Nonceba's little faith in the powers of this world in alleviating her suffering. This interpretation is confirmed in her life story. In her childhood, she was treated like a 'little servant' and there was an absence of intervention from those in her life at the time. She mentioned running away from her aunt's home when she could not stand the abuse:

> One day I got fed-up with horrible treatment and moved to my father's family. My aunt was very upset, she sent the police to come and fetch me. I was forced to go back to my aunt's place.
>
> Nonceba, 77 years old, Grahamstown

This lack of intervention sets a pattern in Nonceba's life. She was emotionally and physically abused by her husband until he died. She interprets the spousal abuse as being sanctioned by the custom of lobola (see 6.2 for a detailed discussion). She has always looked after some of her grown children and grandchildren, including two daughters and a grandchild living with AIDS. She has health problems of her own that require medical intervention. The inadequate help from either the family members or the government services causes Nonceba, paradoxically, to seek help from God the 'cursor': "I cry out to God and ask him why he is punishing me and when is he going to let me off" (Nonceba, 77 years old). A sociological significance found in Nonceba's story is the manner in which she links her ill-health to her social circumstances. She illustrates this association in the following statement, a response to a question on how she is experiencing the New South Africa:

> Mmmm…my child, we are even sick now. Firstly, we are staying in water because we don't have any places to stay in. They keep on saying that they are going to provide for us but we end up using our money from the grant to repair these things. That's why we don't have anything to eat, it's because we are trying to repair this room. As you can see this gravel outside, someone said he was going to help us repair this room. That cost money. And yet this government keeps on saying that we must vote for it. My question is must we vote for shacks? We are even sick, to make matters worse. We are suffering from arthritis, we are deaf and we are blind, but we are not given anything for those. Others have high blood sugar, but if you go to see the doctor, he will tell you that 'I don't see anything wrong with you'. My eyes are itchy and teary and they said I should get those dark spectacles. Then they said I should remove the top layer but I refused because my heart says I shouldn't. The problem with my eyes is that they are sensitive to light and they become itchy, that's all.
>
> Nonceba, 77 years old, Grahamstown

In the above narrative, Nonceba goes beyond her personal ill-health as a result of poor living conditions to include members of her community when she states "others have high blood sugar, but if you go to the doctor, he will tell you that 'I don't see anything wrong with you'". In this inclusion she points to collective suffering within her community and how inadequate medical care and other public services exacerbate their plight.

Nonceba's counterpart, 83-year-old Nomaindia, even though lacking in eloquence, 'spoke' volumes with her body language. She displayed a despondent attitude throughout the interviews, and she rarely looked up when responding to questions. Unlike Nonceba, who sees her life circumstances as 'a curse from God', she seems resigned to her plight. This is illustrated in the following excerpt, a response to the question: When you were growing up, did you have any ambitions or dreams? And if you did, have they come true?

> No, what I used to wish for when I was in difficult circumstances, is that God would keep me and direct me. I didn't have a father at the time, I only had my mother. I didn't want to make my mother suffer. I got married here in Grahamstown, although I was not from here. All my dreams were shattered because I couldn't help my mother anymore.
>
> Nomaindia, 83 years old, Grahamstown

Instead of blaming God, as Nonceba does, she prays for guidance and protection. Her dependency on Providence echoes an earlier discussed observation (see 3.3.3) that God is in control of a believer's life, whatever the circumstances. Surprisingly, it is the daughter of the 'cursed' woman who holds a similar view. Speaking about her relationship with God regarding AIDS, she said:

> I don't blame God because this is His way and it is His plan. He knew that this is the disease that I would get, because each and every person is going to have his or her own sickness. The Bible says there are going to be many incurable diseases. So, when I go to church I remember that, but I also realise that even this disease is eventually going to be curable, because initially TB could not be cured. A person who suffered from TB a long time ago would be locked up all by themselves and could not share even a spoon with another person. But with this, you can still

> share with somebody else and eat with the same utensils. So that shows that it is going to be curable eventually, but it will be followed by another incurable one.
>
> Lulama, 48 years old, Grahamstown

This view of God is shared by 21-year-old Palisa, who is also HIV positive:

> I am not angry with God. I pray to Him for a cure.
>
> Palisa, 21 years old, Grahamstown

5.4.1 Reflecting on childhood memories

The childhood memories of the women reveal aspects of their experience of this period of their past. Significantly, the recollections demonstrate a link between their past and present life experiences, including their AIDS narrative. As discussed earlier (see 3.2.2), memory provides us with a biographical record and enables us to understand and react appropriately to the changing and unfolding experiences.

5.4.1.1 Unpleasant memories

As noted earlier, the underlying theme in the women's story is life-long suffering inextricably linked to the women's past. To continue with 77-year-old Nonceba's biographical interpretation, she makes an explicit connection between her deprived childhood and her present circumstances:

> I grew up as an orphan. I was not raised by my mother because she passed away. My aunt raised me up and I was herding cattle and all those things. I was treated like their little servant, until the day I got married. Yes, I got married. Now even this poor eye sight is a result of the journey I have travelled. Yewh, I was treated like a slave. I was the eldest in that household. I was not allowed to go out and socialise with my friends at dance halls. My aunt used to tell me that I could only start going out when my young cousins were old enough so that they too could come with me. I was given a lot of chores to do while the children of the house hardly did anything of substance. One day I got fed-up with horrible treatment and moved to my father's family.
>
> Nonceba, 77 years old, Grahamstown

For Nonceba, being worked as a 'little servant' in her childhood sets a pattern of difficulties in her lifeworld discussed in 5.4 above. It is for this reason that she equates her biographical history with her present day suffering: "even this poor eyesight is a result of the journey I have travelled". The others also allude to the connection between past deprivation and their dire present. The HIV positive granddaughter Palisa illustrates this when she pins her lack of desire to have children, not on HIV/AIDS, but on life-long poverty:

> I have struggled all my life. I can not afford to look after a child. Nobody can help me do this. Yes, I can say my life is a mess because I can't afford anything since I don't have money. My grandmother is the only person looking after me because she is getting pension money. Nobody cares for me.
>
> Palisa, 21 years old, Grahamstown

Palisa's grandmother, the sole breadwinner for most of her life, compares her life trajectory to that of her mother's:

> I can see that I am also similar to my mother, because there is nobody to help here in the house. I am staying with them and they are unable to help me. I am responsible for everything in this house. It does not bother me, but it would bother me if there was somebody else working in this family, but there is nobody else who belongs to this family, it is just us.
>
> Nomaindia, 83 years old, Grahamstown

By using this comparison, she grounds her present circumstances in her mother's history. Thus, confirming the observation that being born in a poverty-stricken household is a key to long term trend for chronic poverty (May, 1998: 35). This view on intergenerational poverty is shared by Zintle, 23 years old, who continues to experience the grandmother's and mother's poverty. She nonetheless hopes to break this trend:

> I know that my family is poor and that I am the only one with a Matric education, but I love my people. I will do everything in my power to help uplift this family. This is my biggest wish and prayer to God – to enable me to grow old so that I can take care of my family.
>
> Zintle, 23 years old, Grahamstown

5.4.1.2 Pleasant memories

It would be unfair to the women not to write about their pleasant childhood memories. Even though these seem few in between the deluge of bad memories, all the women do hold a pleasant memory of their childhood. Both grandmothers remember having more than enough to eat:

> We used to keep food. We would even put it on top of the table and cover it because you knew that nobody would touch your food. The next day when you want to eat it, it would be sour and you would have to throw it away. I would say it was better in the olden days. Times were better than what I am experiencing now.
>
> Nomaindia, 83 years old, Grahamstown

For the grandmother with a flair for telling a captivating story, she spanned a whole range of ‘good times’, including plenty to eat:

> For me, I think it was much better when I was growing up when compared to what I am seeing now, because we didn’t lack anything when we were growing up. For example, we did not buy things like firewood, paraffin and all that because we lived on a farm. But now you have to buy even my nail, everything. If you don’t have then you don’t have it, you can’t go next door to ask for salt because they will tell you that they don’t have it. We used to attend those traditional ceremonies. They used to be our parties. We used to enjoy ourselves. You would come back and sleep and eat sour milk. We used to harvest in the fields and we would feed on the produce from the fields. Then we started working in the pineapple fields. I don’t think there is even a single thing that I can say was bad when I was growing up, because we used to enjoy everything that we did. We used to enjoy even fighting with each other in the fields, so there wasn’t any bad thing.
>
> Nonceba, 77 years old, Grahamstown

Equally, their daughters talked about nice childhood memories:

> It was nice when I was growing up. There were parties we used to go to and we would dance and dance at those parties. It was fun then and we didn’t have fights. If you had a disagreement with someone, you would disagree and it would end there immediately after that. It was nice.
>
> Lulama, 48 years old, Grahamstown

> It was nice when I was growing up because I was happy. There wasn’t anything bothering me. I was happy because I was living with my parents, and my mother raised me well.
>
> Ntombi, 46 years old, Grahamstown

A major shift from their mothers' happy childhood memories for the daughters is food. For this generation, there are a number of reasons why there was an absence of recalled narratives on 'plenty' to eat. For me, two interpretations spring to mind. First, the daughters may not have had 'plenty' to eat as their mothers did. This suggestion is based on the politically and economically troubling period of their childhood, as discussed in Chapter 1. Second, the daughters' definition of happy childhood memories is different from those of their mothers. For the daughters, food is taken for granted and does not constitute pleasant memories. Similarly, their daughters make no mention of 'plenty to eat' in their recollection of happy childhood memories:

> When I was young we used to have a lot of good times in the house. We are a close-knit family and we shared everything we had. My grandmother used to tell us Xhosa bedtime stories which were very nice.
>
> Zintle, 23 years old, Grahamstown

> I grew up well. I used to play with the other children and my grandmother treated me well and took good care of me.
>
> Palisa, 21 years old, Grahamstown

A common theme running through the pleasant memories of the two granddaughters is the love and care received from their grandmothers.

5.4.2 The impact of past experiences and illness on identity

In narrating their past experiences, the women give us insight into how their lifeworlds are subjectively constituted. This includes how concepts of their identities are shaped and informed. Once again, 77-year-old Nonceba was expressive and detailed in locating her identity within the troubled past. She does this especially in her relationship with her family. Describing herself, she said:

> I can say that I am a very difficult and sometimes aggressive person. At times I fight, because I find talking through issues to be a waste of time. I don't know how to argue. For example, if I get into a fight or quarrel with somebody, I don't forgive or forget easily. I hold a grudge against that person for a long time. I can go as far as saying that I am a cruel person. I can give you another example. Once my stepson accused me of being a witch, just because I was demanding my

> money back that he had squandered. I took great offence at being accused of practicing witchcraft and I demanded that he come up with proof of sorcery. I truly put him through hell for this. I was not at all prepared to let this matter go. He was really scared and he moved out of the house. I still have not forgiven him for he has not given me my money and has not apologised for calling me a witch. I think I am very cruel. I don't like the way I beat up my children or grandchildren when they annoy me. I beat them up so bad that if you saw how badly I beat them you would never believe that this is my flesh and blood. I don't know how to express my anger in any other way when dealing with others. I only respond in a very aggressive manner – shout or beat. I literally get sick if I don't vent my anger on whoever has crossed my path. I can not simply speak in a calm voice about what is bothering me.
>
> Nonceba, 77 years old, Grahamstown

Her granddaughter also locates aspects of her identity within the family. She explains her introvert tendencies in light of her family's alcoholism:

> Sometimes, I like being alone. Even when I am not feeling anything, I enjoy being alone by myself … There is a lot of tension and fighting among family members. I hate this, I love peace and I think I am a peacemaker in this house. I do not like bad relationships and I always try to broker peace between the family members who are quarrelling or fighting. When my grandfather was ill, he only wanted me or allowed only me to nurse or give him food, even though I was young. This was so because he noticed that I was the only one who was not fighting or arguing with others and that I loved peace. I get very stressed when I have to get involved in these fights. I usually go to my aunt's place next door to try and talk to them. I never involve myself physically. I just plead with them to stop. I always tell my aunt that her behaviour is unacceptable and that it stresses my grandmother a lot. Even when I try to ignore these fights, they still stress me as the noise levels are usually unbearable and it disturbs everyone in our house.
>
> Zintle, 21 years old, Grahamstown

Contrary to the grandmother and granddaughter's perceptions of the self, Zintle's mother sees her identity in the light of her AIDS experience. In most of her responses in the interview sessions, she referred to her illness, even when this was not specifically asked. When asked to describe herself, she said:

> I like to take care of sick people. For example, I have a friend who is also HIV positive and I usually go over to her house to help her when she is sick. Her mother always wonders how I manage to do this, seeing that I am equally unwell. I told her that I just love helping others and I know that one day somebody will help me as well.

Lulama, 48 years old, Grahamstown

Helping others, especially her friend with AIDS, may well be Lulama's way of making sense of her changing self-identity due to her illness. This suggestion is confirmed by her claim that "I know that one day somebody will help me as well" (Lulama, 48 years old). In this statement she views her identity as a care-giver and a potential care-receiver when suffering from AIDS-related illnesses. She locates her subjectivity in relationships with others in terms of her HIV positive status and not in the troubled relationships with her family, as her mother and daughter do. Lulama's view of herself is similar to a common observation that chronically ill individuals experience, namely a 'biographical disruption' (Bury, 1982). This, as discussed in Chapter 3, is when a chronic illness disrupts an individual's basic assumptions about her/his identity and her/his relationship with others. As is evident in Lulama's story, a biographical disruption due to AIDS necessitates a rethinking of her pre-ill self. For her, it means drawing on a childhood dream in the construction of her identity as a care-giver:

> I wanted to be a nurse when I was growing up. When we were still going to school, my friends and I would ask each other about what we wanted to be and one would say I want to be a teacher and the other would say she wants to be a nurse. I used to say I don't want to be a teacher because these children are not disciplined and they will give you problems, but when you are a nurse, you are able to see that this person I can be able to help and he is not going to mistreat me after that.
>
> Lulama, 48 years old, Grahamstown

In addition to living out her childhood dream, albeit not as a professional nurse, Lulama gives us insight into how she desires to make her 'spoilt identity' (Goffman, 1963 in Kleinman, 1988: 159) meaningful. As discussed in section 2.3.3, the social stigma attached to AIDS invokes themes and feelings of humiliation, inferiority, boundary violation, personal anguish and self-devaluation (Pattison, 2000: 57). Thus for Lulama, being socially relevant as a care-giver reverses some of these negative associations and adds value to her AIDS identity. Like the Indian participants in an earlier cited study (*Caregivers' experiences of informal support in the context of HIV/AIDS,* see 3.2) who felt the need to reciprocate the help received from others, Lulama is affirming her social significance in her role as care-giver. As she states "when you are a nurse, you are able to see that this person I can be able to help ... I know that one day somebody will help me as well". Helping others and being helped are ideally dependent social phenomena, and underpin the philosophies of *ubuntu* (see 3.2.1) or *krengjai* (see 3.4.1) found in collectivist societies. Importantly for Lulama, care-giving and receiving cushion the disruption of AIDS on her self-identity as experienced by some patients in individualistic societies. Her emotional self is protected from the isolation that is inherent in the experience of a chronic illness, especially AIDS.

5.5 An HIV-positive result as a traumatic event

As is the case with most serious medical diagnoses, the two HIV positive women in this study experienced their HIV results as a traumatic event. In addition to the anticipated physical suffering, the social stigma attached to AIDS (see section 2.3.3) compounded their emotional pain, as well as that of their family members. For these two women and their families, it is in addition to living an impoverished life and having to negotiate its negative consequences. In the case of 48-year-old Lulama, the initial HIV emotional trauma was concurrently experienced with her youngest child's ill-health and HIV positive status:

> I had a child and after giving birth to the child, the child got sick. She continued being sick and I would take her to the clinic where she would be referred to the hospital and she would get admitted. Eventually they asked for my permission to do a blood test on the child. HIV/AIDS then was still new. They told me that the child is HIV positive and they asked if they could do a blood test on me as well. I said okay and they told me that I am also HIV positive.
>
> Lulama, 48 years old, Grahamstown

Lulama's above 'calm' narration of how she received her daughter's HIV positive result does not capture the emotional pain she experienced at the time. Her body language and tone of voice during the interviews gave me an indication of what she may have been feeling at the time of HIV diagnosis for her and her daughter. The sadness in her voice was palpable and she looked visibly pained whenever she talked about the guilt she continues to feel for infecting her child with HIV.

For 21-year-old Palisa, testing HIV positive renewed the anger she harbours towards her family for providing her a ‘horrible life’. Even though she, like the other participants, holds rare fond childhood memories, especially of her grandmother’s care and love, she resents her mother and father’s lack of parental care. When asked to talk about her feelings regarding her HIV status, she simply said:

> I don’t feel well. I am angry. I am angry at my family [she burst into tears after this statement].
>
> Palisa, 21 years old, Grahamstown

Other than this visible display of emotion, she did not seem overly concerned about her HIV status. Unlike Lulama who was already dealing with her child’s AIDS-related illnesses when she tested HIV positive, Palisa did not tell us why she tested. She only told us that she got tested in March, 2005. Describing her feelings when she tested for HIV, she said:

> I was worried. I don’t think about it now. It’s because I went through counselling and the counsellors made me to be strong. They told me to live like other people and not tell myself that I am sick. My mother also told me that I must not always be thinking about it.
>
> Palisa, 21 years old, Grahamstown.

Palisa was much more articulate about the general dire circumstances of her life, than she was when talking about her HIV status. As discussed earlier in section 5.4.1.1 she even attributes her lack of desire to have children on poverty and not on her HIV positive status. To repeat her words:

> I don’t want a child. I did not want to have children even before I knew my status. This is because I have struggled all my life. I can not afford to look after a child. Nobody can help me do this. I can say my life is a mess because I can’t afford anything since I don’t have money. My grandmother is the only person looking after me because she is getting pension money. Nobody cares for me.
>
> Palisa, 21 years old, Grahamstown

Despite the above sentiments, she did indicate a desire to have a child if her circumstances were to improve. Her desire was made known when she responded to a hypothetical question: ‘If someone could support you, do you think that you would want to have a child?’ She said “yes”. In this regard, that is, being concerned about poverty and not an HIV positive status, Palisa joins other women in similar circumstances. These women, like her, view poverty and its consequences to be more threatening than HIV/AIDS. As discussed in section 3.2.2, chronic poverty minimises the disruptive impact of illnesses such as HIV/AIDS on the women’s lifeworld. Thus Palisa’s HIV positive diagnosis “may be just another in an ongoing string of disruptive events” in her life (Ciambrone, 2001: 532). This interpretation is not suggesting that Palisa felt no emotional trauma at being diagnosed HIV positive, it simply highlights the interconnectedness of her lived poverty and HIV experiences. The suffering in the former inevitably adds to the emotional pain experienced in the latter and vice versa.

5.5.1 Suicide as a way out

The stigmatizing nature of AIDS compounded Lulama’s traumatic experience of the double HIV diagnosis. As noted above, testing for HIV was ‘forced’ on her after her sickly daughter tested positive:

> So, it means that the child got it from me. So, immediately when I heard that, I went and told my husband and he didn’t accept it. Then I came here and I told my family about the results. My family was very upset. But I started getting insults in the community, and even my sisters used to swear at me about it.
>
> Lulama, 48 years old, Grahamstown

Before she even experienced stigma from others, she was already blaming herself for passing this disease onto her child. As discussed in section 2.3.3, AIDS is an illness which is socially viewed as self-inflicted through immoral sexual behaviour. This perception causes the individual living with AIDS to internalise her/himself as having “a ‘spoilt identity’, a feeling of being inferior, degraded, deviant, and shamefully different” (Goffman, 1963 in Kleinman, 1988: 159). We can see from Lulama’s story that AIDS stigma may cause an individual to see suicide as the only way out. When the burden of the ‘insults from the community and her own sisters’ as well as her own internalisation of a ‘spoilt identity’ was too much, she attempted to commit suicide.

> I decided to take my own life by drinking car petrol that I got from next door. Before drinking it, I realised that I could not stand its smell. So I decided to take the pills my disabled sister was taking, and I drank all of them. I just wanted to sleep and never wake up. But before I got to my bed, I fell at the door and they saw me and called an ambulance. I told them that I was not going to get inside that ambulance and when the ambulance arrived, I told them that I was not going to get in because they say I am HIV positive so I don’t see the point of being taken to the hospital.
>
> Lulama, 48 years old, Grahamstown

We can only attempt to understand the emotional pain that Lulama must have been experiencing. Her previously held notions of an unspoilt identity were devastatingly shattered by the experience of the social stigma attached to her being HIV positive. The devastation was such that she refused to acknowledge her family’s help in calling an ambulance. In her anguished state she effectively denied to see her family’s care and concern. Her focus was only on the insults. As she reasoned, “I was not going to get in because they say I am HIV positive so I don’t see the point of being taken to the hospital”. For Lulama, it was not only pointless to be taken to the hospital, significantly, it was pointless to continue living with a ‘spoilt identity’ (Goffman, 1963 in Kleinman, 1988: 159). In light of her family’s poverty, one can assume that an HIV positive result caused Lulama to simply want to “sleep and never wake up”. This assumption is supported by her mother’s eloquently expressed dire circumstances of this family’s tribulations grounded in generational poverty. As I have noted earlier, Lulama understandably centred her life story on her AIDS experiences. She said little about her other lived experiences.

5.5.2 ‘Sitting by myself at school’: a daughter’s cry

The emotional trauma related to the stigma of AIDS went beyond Lulama, as it was also experienced by her eldest daughter. When asked if she had experienced stigma regarding her mother’s HIV status, she said:

> I can say, yes. When we found out that my mother was HIV positive, I was still in high school. Afterwards, whenever a group of friends discussed HIV/AIDS, I would move away from there and sit by myself. Then they would ask me why I was sitting alone, and I would tell them that I was not enjoying the conversation. Then another one would ask if there was a problem with what they were talking about and I would just say I didn't like talking about that thing. Then they would call me and say they have stopped talking about it because it bothers me. So as a result, they ended up not talking about it.
>
> Zintle, 23 years old, Grahamstown

Zintle's initial experience of the stigma associated with AIDS, like her mother's, was self-induced shame and maybe anger at her mother for having contracted "that thing". She elected to isolate herself from any discussion on HIV/AIDS as it was a painful topic for her. This, no doubt added to her emotional suffering. Like her mother, she also experienced overt AIDS stigma, though to a lesser degree:

> There were others who would go from one class and tell the others in another class that my mother is HIV positive and then they would start pointing fingers at me. But by the time I finished school, they had stopped doing that because I told them that anyone who makes fun without knowing his or her own status or that of their family members, is stupid.
>
> Zintle, 23 years old, Grahamstown

Standing up to those who 'pointed fingers at her' may indicate an acceptance of her mother's condition. More importantly, she uses it to educate her friends about the prudence of taking an HIV test, instead of 'stupidly making fun' of those who are HIV positive.

5.5.3 'HIV as a weapon': a grandmother fights back

Zintle's grandmother was also emotionally traumatised by the AIDS stigma directed at her two HIV positive daughters. On occasion, she also stood up for her daughters:

> Some other people use HIV as a weapon to bring my daughters down, especially those people they fight with. They call them names because of HIV. I once heard on the radio that name-calling of HIV positive people can land you into trouble, you can even be sued. So I told my daughters to sue these people. A lady who Lulama had borrowed money from once came here and started shouting at her.

> She kept on referring to her HIV positive in her insults. This lady was very disrespectful and I got annoyed and told her to go away before I beat her up.
>
> Nonceba, 77 years old, Grahamstown

Fighting for her children's dignity, for Nonceba, included chastising one of her daughters who 'used HIV as a verbal weapon' against her HIV positive sister:

> Nosipho [pseudonym, the other HIV positive daughter. Not a participant] used to be very mean to Lulama as well, with regard to her HIV positive status. Whenever the two had a fight she always brought up the HIV issue and used it as a weapon. This was before she herself tested HIV positive. I remember the day she knew that she was positive she was very ashamed and shocked. I reminded her how she used to be horrible to the sister, in a way I was being vindictive. I couldn't help myself, because Nosipho used to be very mean and used to laugh at her sister's HIV positive status.
>
> Nonceba, 77 years old, Grahamstown

5.5.4 The confusion of a grandmother

Nonceba's contemporary, 83-year-old Nomaindia, stays with two grandchildren living with HIV/AIDS: a granddaughter who is HIV positive and a grandson who has full blown AIDS, and is on ARV treatment. Talking about her feelings regarding the granddaughter's recent HIV diagnosis, she simply said:

> I don't know because I have never seen it before. I don't know really … I felt sad inside when they said she has this. Yes. I said I wonder where she got it from, my God, because I don't know it.
>
> Nomaindia, 83 years old, Grahamstown

Her ignorance about AIDS may, in this instance, be bliss because it cushions any AIDS-related stigma from the community. This suggestion is confirmed in her response to the question on AIDS stigma:

> I have not noticed anything. I am still living in peace. I have not seen anything strange.
>
> Nomaindia, 83 years old, Grahamstown

Her ignorance also spares her from the emotional and medical concerns over potential AIDS-related illness for both grandchildren. When we conducted the interviews she had not yet cared for or seen the serious AIDS-related illnesses that her grandson has experienced. He spent a long time in a TB hospital. At the time of the interviews he had discharged himself from the hospital and appeared to be in relatively good health. The grandson also confirmed that only his aunt, a participant in this study, nurses him when he is ill:

> When I am not feeling well my aunt looks after me. For example, she used to rub my legs when I got home from hospital during the weekends. My legs used to be sore.
>
> Mbulelo (pseudonym), 36 years old, Grahamstown

5.6 Emotions attached to living with HIV/AIDS

For the participants in this study, negative emotions are not only reflected in their HIV/AIDS narratives, but are evident throughout their life stories. However, since a major aim is to show how AIDS impacts on the three generations of women, it is imperative that I present and discuss some of the emotions attached to HIV/AIDS. This is in addition to other emotions that are inherent in the narratives throughout this chapter and Chapter 6.

5.6.1 'I have a lot of sadness'

Sadness, as pointed out in Chapter 2, is a common emotion in those living with a chronic or serious illness. For 48-year-old Lulama, whose youngest child is also living with AIDS, sadness arises from both her child's and her own illness experiences:

> I am very sad, in great emotional pain and I bitterly regret having passed on this virus to my child. It would have been better if I was the only one who was HIV positive. I have a lot of sadness regarding our being HIV positive, because I have no control on who will die first between Nozuko (pseudonym) and me. My wish and prayer to God is that he takes her first or that she becomes ill first so that I can nurse her and be there for her.
>
> Lulama, 48 years old, Grahamstown

In this expression of sadness, Lulama is equally expressing the guilt that she still feels for having infected her child. As shown earlier, this guilt over her daughter's illness was central to her attempted suicide when they tested HIV positive. Now that she has accepted her illness, she is still saddened by the inability to ‘control’ who will die first. Compounding this sadness is the reversal of roles between her mother and herself:

> It worries and pains me a great deal, especially now that she is old and we are the ones who are supposed to be looking after her. I feel very helpless, because I should be helping her as she has physical problems and yet she is the one caring for me. Sometimes I pretend that I am well when I am feeling very sick because I don’t want her to worry too much or do everything for me.
>
> Lulama, 48 years old, Grahamstown

This sentiment is shared by her mother:

> How do I look after her anyway, because I end up letting other people take care of her because I am unwell myself. I feel sad because she is ill. She is ill. You know, sometimes I become sicker than she is. When people are looking after her and lifting her up, I can’t do anything. To me it is as though she is going to get worse if she is held in my hands. Yes man, you know … This is my first born, so when she is sick I become sick also [very emotionally narrated and was crying].
>
> Nonceba, 77 years old, Grahamstown

Similarly, Lulama feels the same about her eldest daughter taking care of her:

> It does bother me a lot and I once told her that she must go out and socialise and not just sit around me … She is still young to cope with all the demands of running a household. My wish if I die now is for somebody older, like a social worker, to help her in caring for her siblings.
>
> Lulama, 48 years old, Grahamstown

Even though Lulama’s daughter shares her sadness, and may even find care-giving burdensome, she nonetheless disagrees with the suggestion that ‘she is still young’ to mother her siblings:

> No I don’t agree with my mother. I don’t see myself as a child or young, somebody who can’t look after her siblings. I see myself as a mother to them even now, because I already perform this role – I cook, give Kuhle [young sister with AIDS] her medication and prepare her for school, I buy groceries and perform other household chores. So even if my mother were to die today I will cope as I am already looking after them.
>
> Zintle, 23 years old, Grahamstown

The other set of mother, daughter and granddaughter, as I noted in their introductory biographies, were not as expressive about their feelings regarding the granddaughter's or grandson's HIV/AIDS status. For example, when the HIV-positive granddaughter was asked to describe her emotions regarding her status, she simply said:

> I was worried when I was tested. I don't think about it now.
> Palisa, 21 years old, Grahamstown

Her mother and grandmother were similarly abrupt in talking about their feelings in relation to Palisa's HIV status:

> My heart is sad, but I have comforted myself.
> Ntombi, 46 years old, Grahamstown

> I felt sad inside when they said she has this.
> Nomaindia, 83 years old, Grahamstown

For this family, the burning issue is poverty, not HIV/AIDS. They show and express more emotion when talking about the household's only source of income, namely the grandmother's old age grant, than they did when talking about HIV/AIDS (see 5.6.2.2 below). Again, as other studies have shown, living in chronic poverty and its negative consequences (Baylies & Bujra, 2000; Ciambrone, 2001; D'Cruz, 2002, 2004), do indeed minimise the disruptive impact of a serious or chronic illness on the individual's lifeworld. The onset of a serious chronic illness, as evidenced in the stories of this set of grandmother, mother and daughter, is seen as yet another calamity in the circle of life filled with hardship.

5.6.2 'Are others as angry as me?': no twilight years

As the reviewed studies show (see Chapters 2 and 3), grandmothers in sub-Saharan Africa and other poor nations face enormous challenges when AIDS enters their homes. Beyond their own physical, emotional and financial difficulties, they are expected to carry the burden of care for their AIDS-stricken adult children. Often, they also become the primary carers of grandchildren, whose parent is living with AIDS. The two women in this study are similarly affected.

5.6.2.1 The experience of AIDS and alcoholism

The anger experienced by the grandmothers in this study in relation to HIV/AIDS emerges in the other lived experiences, and not just in the phenomenon of AIDS. In expressing the anger attached to HIV/AIDS, the women draw on their past and present difficult lifeworlds. A good illustration is 77-year-old Nonceba's eloquent weaving into her web of woes the anger she feels towards the two daughters' HIV/AIDS condition. This, to repeat her earlier cited lament, transfers the AIDS anger into other lived angers:

> Sometimes I feel like God has cursed me. Because it doesn't seem that other people are as angry or hurt as I am and they don't have bad things happening to them, like I do. It seems as if I am the only one having all the bad things happening in her life. It is like God has something against me. I am afraid to speak it out because I don't want her to hear me say that [she is referring to her daughter with AIDS, who was in the room when this interview was conducted]. How long have I been suffering? Since I was a child I was suffering up until now. Now that I should be resting, yet I am still suffering.
>
> Nonceba, 77 years old, Grahamstown

Although, Nonceba admitted to being an aggressive person (see 5.4.2 above), she contradicted herself when responding to the questions: Do you ever vent your anger at your two daughters who are HIV positive? Do you feel that they have brought more problems in your life? She initially said, "Ayi, ayi [no, no] I have never". At a later stage she talked about the anger and inherent frustration she experiences in caring for her daughter with AIDS:

> Yewh! My daughter has been very ill on a number of occasions. One time when she was extremely ill, she couldn't see and was hallucinating due to the illness. I got very afraid and I decided to take her to a Reverend for prayers and what I thought would be the last rites. She pulled through, but the hallucinating continued. But I am not sure whether this was from the illness or from drinking. She used to drink a lot around this time. Coming to the actual nursing experience, my daughter can be very demanding. Her appetite is usually very poor and she asks for all sorts of foods. You prepare this, she says no because the smell is giving her a headache. She asks for something else and it is the same story. It is

> very tiring and I sometimes get frustrated with her to the point that I chase her and the sister away from this house when she has improved and starts drinking. When people ask me how I can do this, because nobody will look after them when they get sick, I tell them that I am only taking a break and that I will go to wherever they are staying to nurse them. I know that I am ultimately responsible for their care and nursing.
>
> Nonceba, 77 years old, Grahamstown

A larger part of the AIDS anger towards her daughters is related to their alcoholism. In addition to this daughter's drinking problems, Nonceba spoke about how her other daughter [non-participant] with AIDS also drinks and causes problems. Both daughters' alcoholism distresses her to the extent that she sometimes chases them from her house, as she expressed above. In the following narration, Nonceba continues to express this anger:

> Another reason why I wanted her out of the house is, since she found out that she is HIV-positive, her drinking has worsened and she does not look after herself properly. So I thought that I would be better off not seeing how my daughter was further ruining her life with alcohol and fights. I did not want to see this, so she had to go. She becomes extremely aggressive when she is drunk and she threatens to beat me up. So I am in a way scared of her when she is drunk. However, after a while I thought to myself that I was being unfair to her. I saw my behaviour – chasing her – as being 'apartheid' as I had never chased her big sister, Lulama [participant in this study], when she used to behave in a similar manner. She did move out for a short while, but she is now staying with us, in the room next door.
>
> Nonceba, 77 years old, Grahamstown

Her experience resonates with other grandmothers living in similar conditions, discussed in Chapter 3. For these grandmothers, AIDS care-giving is done under difficult physical, financial and emotional strain. To compound this burden of care, most of these grandmothers are the primary providers for the grandchildren (see 5.6.2.2 below). Nonceba's contemporary also experiences alcohol-induced aggression from her HIV-positive granddaughter. This is illustrated in the following excerpt, a response to the question: Do you think Palisa's behaviour and anger towards you is related to her HIV status?:

> Yes, because before she knew her status she was right. When she found out she was HIV-positive she became very aggressive, VERY AGGRESSIVE [says this very emphatically in a loud, energetic voice]. And she displayed extremely aggressive behaviour. She could take anything and throw it at you. But she has

> calmed down a little bit after somebody talked to her [she was counselled by the Grahamstown Health Development Forum lay-counsellors]. Palisa must also stop drinking and she must only drink her medicine.
>
> Nomaindia, 83 years old, Grahamstown

5.6.2.2 How do the grandmothers cope financially?

Both grandmothers in this study provide the most stable source of income in their households, namely old age social grants of R780.00 per month. Nonceba, 77 years old, has a daughter and a granddaughter who currently receive AIDS grants (R780.00 per month each), but these grants are conditional. Mrs Mcuba, the manager at the Grahamstown Health Development Forum and a translator in this study, explained the conditions attached to an AIDS grant. HIV-positive individuals with TB and a CD4 count that is below 200, and with limited income, automatically qualify for an AIDS grant. The grant is, however, stopped once the TB is treated and the CD4 count goes above the 200 mark. Nonceba's other daughter with AIDS used to receive a grant which was stopped after successful TB treatment and an improvement in her CD4 count. A CD4 count reflects the state of the immune system and is used as an indicator of the health of an HIV infected individual (Morris & Cilliers, 2005: 85-6). Asked if any of her children, including sons, support her financially, she said:

> Yewh! I have no child who gives me money [spoken in a subdued and sad voice]. They actually ask me for money. For example, one of my grandsons from my son in Addo was once taken into custody for drunken driving by the Grahamstown traffic officers. His father came to bail him out, but he didn't have enough money and he asked me for the balance. I gave him and he told me that they were going to pay me back. I have yet to be given my money. He doesn't care, because he knows that I need money to run this household, every cent I can lay my hands on. We are often short of supplies such as paraffin and certain groceries, and he is aware of this and yet he does not care. Even his son, the one I helped to bail out, doesn't care for us. He is a taxi driver and he stays here in Grahamstown.
>
> Nonceba, 77 years old, Grahamstown

In Nonceba's household, the aggregate income at the time of the study was R2 340.00 per month, which is used for the upkeep of seven people. As Nonceba shows above, it is not nearly enough to sustain this family, and cannot meet the needs of the daughter and granddaughter living with AIDS. Nonceba herself has medical needs that are expected to be met with this meagre income:

> I am unwell myself … Sometimes I become sicker than my daughter with AIDS. My eyes are itchy and teary, and they said I should get those dark spectacles. Those glasses are expensive for nothing. I paid R180.00 for them and yet I saw a similar type at Checkers for a far less price than I paid. Then they said I should remove the top layer, but I refused because my heart says I shouldn't.
>
> Nonceba, 77 years old, Grahamstown

Nonceba's contemporary, Nomaindia, is in a similar, if not worse predicament. Although her household consists of only four people, compared to Nonceba's eight, she has no control over her R780.00 per month old age social grant. A grandson, who lives in a different area within the Grahamstown informal settlements, collects and administers Nomaindia's social grant:

> My legs give me problems and I can't walk properly. And I can't afford to take a taxi as there is no money when it is time to go. This is why I have asked my grandson to collect the pension on my behalf as he is stronger. Before he started managing the money, Mbulelo [grandson who stays with her] used to handle it, but there were problems. He used to crook me. Then I said no more [emphatically spoken]. After this we decided that Mbulelo should stop handling the pension. We needed somebody within the family to take over. This is why this grandson of mine who does not stay with us handles the money now. Mbulelo used to lie when telling me what he did with the money.
>
> Nomaindia, 83 years old, Grahamstown

Sadly, for Nomaindia, the current administrator also 'crooks' her. He hardly buys adequate groceries. Ntombi, 46 years old, Nomaindia's daughter and mother to the current pension administrator, articulates the problems that the pension set-up has caused in this household:

> I am very upset with the way my mother has given my son the responsibility of managing her money, when I am the one who is expected to look after her. I would rather be away from this house than see my mother starving as there is usually no food in the house. I have always asked my mother to talk to Sipho [pseudonym] about his mismanagement of the money, but she never confronts him. I have indicated to her that her keeping quiet on this matter gives Sipho the impression that I just want to control the money. He thinks that since the owner of

> the money does not complain then everything is okay. I need my mother's support on this issue. He brings small amounts of groceries and he never gives us any money. He owes money to loan sharks and they have my mother's bank card. They withdraw whatever money he owes them from the pension. I am fed-up with this situation. Last month I told Sipho to come and stay with my mother as I intend to move out. This is because I also have obtained loans to buy groceries as what he brings us is very little. My creditors are bothering me and I do not have the means to pay them. When I explained this to him, Sipho said that he was only responsible for credits that he knows about and not those made by others. He said that he could only pay for my mother's credit and not mine, and yet the money was borrowed to buy groceries for this house. He seemed worried when I told him that I was going to move out, and he promised to give me the bank card. He has not done so and every time I go to his working place he ignores me or when he talks to me he is very moody. So I don't know if and when he is going to give me the card [spoken with a lot of emotion].
>
> Ntombi, 46 years old, Grahamstown

Ntombi's threats to leave her mother might be made true, for she was not at home on three out of our five interview visits to their home. For example, at the conclusion of one of the interviews when she was not home, her mother said:

> When my daughter comes I am going to tell her that the people from the government came and that I told them everything, the whole truth – 'how you leave me alone; that you went out last night and never came back; that you stay with a boyfriend as if you are married'. I was not brought up this way. We did not sleep with our boyfriends before we got married to them. I do not like what my child is doing.
>
> Nomaindia, 83 years old, Grahamstown

5.6.3 'I fear for my children, when my mother and I die'

When expressing this fear, the two main participants, Nonceba (mother) and Lulama (daughter), were for once, at a loss of words. This is shown in their uncharacteristically short responses to the question on the future of Lulama and her sister's (also with AIDS) children:

> The bad thing is that Lulama is my supporter or my partner. My worry is that if she passes away, what will I do with these children? That's the question that disturbs me a lot and raises my blood sugar levels.
>
> Nonceba, 77 years old, Grahamstown

Her daughter was similarly inarticulate, when she talked about her concern for not having a home of her own:

> What I wish for in my life since I am not healthy or well anymore and since things are becoming more complicated, I wish that I can have a big house, so that no matter what happens to me, my children can have their own home and not be bothered by other people.
>
> Lulama, 48 years old, Grahamstown

Regarding her daughter with AIDS, Lulama's fear is that she may die before her daughter:

> My wish and prayer to God is that he takes her first or that she becomes ill first so that I can nurse her and be there for her.
>
> Lulama, 48 years old, Grahamstown

She further spoke about her strained relationship with her brothers and her fear that they will not look after her children when she dies. Her brothers had initially helped her when she tested HIV-positive. This help has since stopped:

> They no longer help me. I think it is because they have their own family responsibilities and maybe their wives stop them from helping me financially. Our relationship is not good any more. I actually fear for my children, when my mother and I die. I know that they will not be looked after by my brothers and as such I would rather strangers took them in. Even social workers would be a better option for them.
>
> Lulama, 48 years old, Grahamstown

This fear for the welfare of children is in addition to a fear inherent in those living with a serious chronic illness, such as AIDS or cancer (see 2.3.4). As earlier indicated, the fear involves "our fear of death, which blends with our fear of our suffering in dying" (Riezler, 1944: 489). For Lulama, it involves her imagined fear that her family may not be able to adequately care for her during her terminal stage. In the following narration, she expresses this fear by telling us how she tests her family's capacity to care for her on the deathbed. This was in response to a question whether she is able to discuss her illness fears with her mother and daughter:

> Yes, I do talk to them because sometimes I ask what they would do if I died suddenly. I tell them to lift me up and wash me in order to demonstrate what they would do if I died. This other day, I pretended as if I was very sick and I told them that I felt like porridge and I want to see if they are going to be able to feed me. And they actually did it. So I got up afterwards and I said, 'I can see you still love me'.
>
> Lulama, 48 years old, Grahamstown

Even though Lulama did not mention the word fear in the above expression, she nonetheless managed to talk about the dreaded topic, death and dying, by trivialising it. In pretending to be dead or ill, she manages to articulate her feared final days, when she will have no control over her body. Her enacting the dying process, in my view gives her agency to make sense of her impending death. By this I mean that the sought-after knowledge that her family will carry out the necessary procedures when she dies, lessens her fear of dying. Significantly, it is comforting and empowering for her to know that her final moments will be as she imagines them now. After her family feeds her while she is pretending to be gravely ill, she gets up assured of their love, and declares "I can see you still love me". Lulama's construction of her dying scenario demonstrates the cushioning effects of collectivism (Ubuntu) as discussed earlier (3.2.1). This is the idea that an individual's illness and its devastating consequences are shared by the collective, especially the family.

5.7 Concluding comments

The interpretation of the women's stories has focused on chronic poverty and HIV/AIDS narratives. The two themes, as other researchers have found, are intricately linked. For example, a 'biographical disruption' (Bury, 1982) or 'loss of self' (Charmaz, 1983) due to HIV/AIDS, for the two women is embedded in their experience of generational poverty. Palisa, 21 years old, epitomises this conclusion. She explicitly talked about poverty being of greater concern to her than being HIV-positive. Rationally, she pins her lack of desire to have children on poverty and not on her HIV status. This is the story of her family. Both her mother and grandmother also privileged their poverty narratives above her HIV status and her male cousin's AIDS. In the concluding comments to Chapter 3, I asked the question: How, then, does one tease out 'biographical disruption' that results from chronic illness among the chronically poor? The answer to this question is multifaceted as it involves a complex interplay of illness and poverty narratives, as I have shown throughout this chapter. Both living with HIV/AIDS and poverty experiences have a disrupting effect on the two HIV-positive women. For the woman with full blown AIDS, illness narratives are more pronounced than for 21-year-old Palisa. However, even for her, the underlying theme is poverty, because both her mother and daughter privilege their dire socio-economic circumstances above her AIDS narrative.

This finding, to an extent, is in contrast to a 'biographical disruption' (Bury, 1982) or 'loss of self' (Charmaz, 1983) brought on by chronic or serious illness among the wealthy. These two concepts refer to the notion that the underlying existential assumptions that individuals living with a chronic illness hold about themselves and the world are disrupted at the onset of the illness. For the wealthy, making sense of their illness experiences, unlike the women in this study, is centred on issues of ill-health and not other living conditions. However, for the women in this study and others living in similar socio-economic conditions, disruption in one's selfhood due to an illness is experienced and interrogated within other disrupting lived experiences. In the following discussion, I focus on gender, especially the effects of patriarchy on the women's biographies. Both households, as I have already indicated, are headed by women and are female-dominated. This absence of men inspired the title of the next chapter: 'Where are the men?'

CHAPTER 6

WHERE ARE THE MEN?

6.1 Introduction

The preceding chapter focused on the women's chronic poverty and the emotional, physical and economical impact of HIV/AIDS on the three generations. The discussion in this chapter shifts the focus to the effects of men in the women's lives. To answer the title's question in short, there are no men, save for a grandson in each of the participating households. The lack of men, however, does not mean the absence of patriarchy and its consequences. The very absence of the men is in itself a form of abuse, both on the emotional and material levels. I will explain this claim when discussing the effects of absent fathers on the granddaughters. All the six women explicitly or implicitly talked about emotional and physical suffering caused by the men in their lives.

6.2 Married life

The first two generations in both households were once married. Both grandmothers are widowed, one daughter is divorced and the other daughter's former husband died of an AIDS-related illness. Speaking on her married life, the eloquent Nonceba, 77 years old, confines her narrative to bad experiences. This, despite the question: Can you tell us about your married life, both good and bad times?

> My married life was very bad and I had a lot of problems with my husband. Right from the start of my married life, my husband had always cheated on me. He drunk a lot, constantly slept out, beat me up and never provided adequate food or shelter for me and the children. I grew up in the time where you were not meant to question or challenge your husband's behaviour. I can give you an example: One night he came home drunk and I asked him why he behaved in this way. He beat me up so badly and I sat up and cried all night.
>
> Nonceba, 77 years old, Grahamstown

She reflected on the oppressing Xhosa tradition of lobola (bride price), which contributed to her husband's abuse:

> What saddened me the most is that I was powerless in doing anything and I had nowhere to run to. If I went back to my aunt's home, they would have sent me back because the custom was that once 'lobola' is paid one no longer belonged to her family. She was the husband's 'property'. Once one is married one has to endure all the hardships that came with being married – good and bad; battered and loved; everything.
>
> Nonceba, 77 years old, Grahamstown

In addition, her husband lost his job on the farm due to ill-health:

> My husband had always suffered from asthma and when it got worse he was fired from the job at the farm. After a while we got evicted from the farm house and we moved to Grahamstown. At the time we moved here, there were no shacks or informal settlements. We had to squat with some families, before we built our own place. My husband's abuse continued and our landlords were shocked at how badly my husband treated me. They said that they had never seen such terrible wife abuse before. I used to pray to God that he would change my husband to what he was before we got married. He used to be a sweet somebody and was very good to me, then. We finally managed or rather I managed to build a mud house of our own, because my husband never helped. He just used to lie down and do nothing. During the plastering I lost my ring and I took this to be a sign that our marriage was no more in the real sense. When we moved into our house, we were so poor that we couldn't even afford to put up curtains on the windows and anyone passing by our house could see what was going on inside.
>
> Nonceba, 77 years old, Grahamstown

Nonceba's married story is one of suffering on all levels, which no doubt affected her children, including Lulama. However, contrary to her mother's portrayal of an uncaring and abusive husband, Lulama casts her father in a slightly different light. She talked about him as a disciplinarian:

> In 1983 when I was still working at the fields, I got pregnant. It was a big issue with my father because I was not married and he was angry at me. But after I gave birth they accepted me and there was peace again.
>
> Lulama, 48 years old, Grahamstown

She also spoke about one of her life's regrets, namely ignoring her father's wish for her to continue with her education:

> I do regret that I chose to go to the farm to work and not continue schooling as my father wanted me to. I am sure that I would have led a different life from the one I am leading now.
>
> Lulama, 48 years old, Grahamstown

Lulama spoke very little about her own married life. She has two children from an earlier relationship, before she got married to the father of her youngest daughter with AIDS. She spoke about her late husband, whom she had divorced prior to his death, only in relation to HIV/AIDS. For example, when she tested HIV-positive, she said:

> Immediately when I heard that I was HIV-positive, I went and told my husband, and he didn't accept it.
>
> Lulama, 48 years old, Grahamstown

Her husband's reaction to the news of her HIV-positive diagnosis, led to her attempted suicide, discussed earlier in section 5.5.1. In addition, her husband hid his HIV-positive status from Lulama:

> He never told me that he was HIV-positive. He only told his mother, who later told me. She told me during the funeral of one of his sisters who had died of AIDS. The funny thing is that my husband only came to tell me about his status when he learnt that I was about to start receiving an AIDS grant. He said that he was glad that we were both going to be getting the grants and this would enable us to live comfortably. He was by then receiving a disability grant for his mental illness. He pleaded with me not to disclose my status to people and that I should stop attending the support group at the clinic or to go for HIV medication. However, I ignored him and I am a member of a support group and I am on ARV treatment.
>
> Lulama, 48 years old, Grahamstown

In the above narrative, Lulama alludes to financial stress in addition to the emotional pain caused by her husband. The husband's timing of the disclosure of his HIV status to Lulama shows that he was only concerned about living 'comfortably'. Her AIDS grant is seen by him as a source of income for a comfortable life and not as a desperately needed medical supplement for Lulama. His inconsiderate recommendation that she stops attending the support group and stop taking medication suggests a callousness that is common in patriarchy. By this I mean that he had been conditioned by patriarchal dictates, especially surrounding a ‘lobola’ marriage. A woman is seen as bought property and any financial or material gain within the marriage is controlled by the man. Lulama’s assertiveness on the topic and eventual divorce shows a drastic change from her mother’s ‘acceptance’ of her abusive marriage, as discussed above.

This interpretation of a lobola marriage is supported by the marital stories of Lulama’s mother and her contemporary, 83-year-old Nomaindia. Both women looked after their husbands. In Lulama’s mother’s case, she literally built a house, which ironically belonged to her husband and will be inherited by Lulama’s brothers. This worries both Lulama and her mother, that when they die her children will be chased from the home. Lulama’s brothers have already started laying claim to their mother’s house as her daughter points out below (see also 5.5.1). The following interview transcript with Lulama’s daughter sums up some of the gender dynamics inherent in lobola marriages:

Interviewer: Your mother’s other fear was that none of the family members will be able to help you and your siblings. She also expressed a wish to build her own house before she dies as she fears that you will be chased out of this house once she and your grandmother dies. Do you share these fears?

Zintle: There is a possibility that this can happen – being chased out of the house. I remember when my grandfather died, one of my uncles told us that he was the rightful owner of the house. He said that he was only allowing us to stay, because my grandmother was still alive. When she dies we would have to move out. I told him that we would never stay somewhere we were not wanted and that we would move out and leave the furniture behind, even though it was bought by my mother.

Interviewer: Who does the house belong to legally?

Zintle: It belongs to my two uncles who do not stay here.

Interviewer: Both your mother and grandmother expressed their worries concerning the house. Do they ever sit down as a family to try and resolve this issue before it is too late for you and your siblings?

Zintle: There have been family meetings. My uncles once jokingly said that they would chase us out when my grandmother died, and I believed them. However, my grandmother challenged them by

> telling them that the house and the furniture belonged to my mother. But I don’t think they took her seriously and I worry about this because nothing is written down to this effect – my grandmother’s claim that the house belongs to my mother. So when they are both no longer here, we could be chased from the house.

The other set of mother and daughter had little to say on their marriages. The mother, unlike her contemporary Nonceba, had only good things to say about her marriage:

> My marriage was good. My husband was a stable man, he liked to stay at home and he never drank. He never even looked at other women. He was not like the young men of today. One day, on a Sunday, he was coming home when he got attacked by some young men. They stabbed him. My husband managed to come home and we noticed that he had three stab wounds. He told us what had happened to him. We took him to the hospital for treatment. He was treated and discharged, but he only lived for three days. Then he died at home.
>
> Nomaindia, 83 years, Grahamstown

This picture of a ‘stable man’ may be contradicted by Nomaindia’s self portrayal throughout her life, as the main provider for her children and grandchildren. This may suggest that her husband was also dependent on her. From her story and those of her grandchildren’s, Nomaindia may have been burdened with financial responsibilities during her marriage when her husband should have been sharing the load. The reversal of roles between her husband and herself, namely being the main provider instead of her husband, is similar to her contemporary, Nonceba. While Nonceba built a physical house on her own, which technically belonged to her husband, Nomaindia was the economic pillar in her home, which was also seen as her husband’s. Both these husbands lived off their wives’ brawn and financial acumen. The story of these two grandmothers is the story of most rural grandmothers in developing countries (see Bozzoli, 1991; Gulati & Bagchi, 2005). They are responsible for the well-being of their husbands and children and yet, because of patriarchy, it is the men who are accorded a privileged position in society. This gender positioning, as evidenced in 77-year-old Nonceba’s story, contributes to household male violence towards females.

The interpretation of Nomaindia's narrative above on her husband as a 'stable man' is confirmed by two of her grandchildren, participants in this study. They both spoke of their grandmother as being the main provider, especially for school needs. They cite their grandmother's inability to adequately provide for them education-wise as the reason for leaving school:

> I left school because I did not have school uniform. My father gave me some money occasionally, because he is unemployed. My grandmother was responsible for my school needs. My mother used to stay in Port Elizabeth, then. My grandmother is the only person who used to look after me, even now, as she gets pension money.
>
> Palisa, 21 years old, Grahamstown

Palisa's cousin has a similar story about their grandmother as the provider, and is equally silent on the help from the grandfather:

> My grandmother was the only one looking after all of us and she was poor. She couldn't afford to pay for my school fees, so I left school.
>
> Mbulelo, 36 years old, Grahamstown

In the above example of the grandchildren, it is not only the grandfather who is missing, but the fathers as well. Although the granddaughter acknowledges sporadic financial support from her father, he is physically absent from her life. She has always lived with her maternal grandmother. Thus, one can ask again: Where are the men? As I stated in the introduction to this chapter, a father's absence may be a cause of untold emotional and physical suffering for the growing child.

6.3 The emotional impact of absent fathers on the granddaughters

As discussed in Chapter 1 (see 1.3), the African family life suffered a negative blow when migrant labour 'normalised' absenteeism of the fathers. The children, as Ramphele's (2002) earlier cited study shows, suffered and continue to suffer the most, both emotionally and financially when a father is not present. In this section, I explore the emotional impact of absent fathers on the third generation of women. Both women have been brought up by their maternal grandmothers. As 21-year-old Palisa says above, her father sporadically supported her financially, but was physically absent from her childhood. One can therefore understand Palisa's earlier expressed anger towards her family for providing her with a horrible life (see 5.4). Her peer, 23-year-old Zintle, shares this familial resentment, particularly towards her father and his people:

> My father had never, never, ever done a single thing for me and my brother. I do not at all regret not having had a relationship with him. I always tell myself that he may have been unable to help my brother and me, as he had so many children with different girlfriends. I am sad that he died without us having mended or given our relationship a chance to grow. Maybe if he was still alive we could have made an effort of developing a relationship and we would not be feeling so alone – especially in light of my mother's illness and possible death at an early age. We could have a family to help us out [her father and his family].
>
> Zintle, 23 years old, Grahamstown

In Zintle's account above, one can see various emotional consequences attached to her absent father. To start with, she seems bitter about her father's lack of financial support: "My father had never, never, ever done a single thing for me and my brother". In her next statement, she says, "I do not at all regret not having had a relationship with him". Although she articulates her bitterness towards her father by stating her remorselessness, she nonetheless goes on to rationalise his lack of financial or any other support. She excuses him or tries to understand his 'unfatherly' behaviour by pinning it down on his having "many children with different girlfriends". Making sense of her father's absenteeism culminates in her expression of sadness "that he died without us having mended or given our relationship a chance to grow". In this expression one sees the emotional need to connect and relate to her father. Significantly, it also highlights the role that the negative emotions attached to her father play in how Zintle views her unfolding selfhood. This significance is premised on the fact that emotion influences memory and interpretation of everyday life experiences and the emerging narrative of the self (see 4.2.2). It is possible that Zintle's understanding of her father's absence is only in hindsight. When she needed her father's financial support she might not have been this empathetic about his 'other children' or any other reason that she retrospectively attributes to his lack of support. To repeat an earlier observation (see 4.2.2), we remember selectively, and sometimes "confer meanings on experience that did not possess these meanings at the time of their occurrence" (Freeman, 1993: 8).

Compounding the emotional pain attached to her father for Zintle, is her mother's failing health and the possibility of an early death. For this, she wishes she had had a relationship with her father, so that "we (her brother and herself) would not be feeling so alone". When Zintle was asked if she has a relationship with her father's people, she said:

> I do visit them and I always attend the big family occasions such as funerals. It is not easy for me to go often as they stay in Bathurst and I do not have transport money to go there. However, they never help us financially or otherwise. I am the only one who makes the effort of visiting them. For example, I asked one of aunts to help me with my Matric farewell gown. I never got a cent from her or anybody else from my father's people. But I still visit them regardless as I consider them as my family.
>
> Zintle, 23 years old, Grahamstown

From this utterance one can interpret that Zintle desires a relationship with her father's people that will, somehow, proxy the non-existent relationship with her late father. This desire to connect with her father's family points to a basic need for emotional ties with one's family, which determines what gets into our narratives of self (Hardcastle, 2003: 353-55). For Hardcastle and others (e.g. Lupton, 1998: 168), "our idiosyncratic desires guide our existence, and as these remain constant over time they allow us to hypothesise a common core that powers our behaviour" (2003: 354). This means that Zintle's emotional need to have a relationship with her paternal family forms a significant part of her life story. It also influences her behaviour, namely visiting them even if they do not make the effort: "I still visit them regardless as I consider them as my family".

Zintle's instinctive need to connect with her paternal relatives is shared by Mbulelo, 36 years old, a grandson of 83-year-old Nomaindia. Although he is not part of the original research design, I decided to include his 'absent father narrative' as it gives us insight into the way sons and not just daughters are negatively affected by this phenomenon. Of relevance to this study, his life story enriches our understanding of his grandmother, aunt and cousin's stories. He was more articulate than his three female relatives. Like his cousin Palisa and Zintle, he too grew up without a father, and only met his father when he was a working adult. Like Zintle, he also desires to have a relationship with his father's family:

> I have an aunt on my father's side. My father passed away in 1997, but before he died he had established a relationship with me and introduced me to his relatives. I have a half brother and sister from my father. It seems like they only want me when I have money. When I used to work at Hi-Tech, they visited me often. But now that I am not working they don't visit me. I am the only one who goes to see them.
>
> Mbulelo, 36 years old, Grahamstown

Like Zintle, he is also the only one who visits his paternal relatives. For these two, one can speculate that they are emotionally hurt by being 'rejected' a second time, this time around by their paternal relatives. The lack of reciprocity in this interaction negatively influences Zintle's and Mbulelo's sense of self. This involves the negative emotions inherent in being socially marginalised, especially by one's own father and relatives. Significantly, these two may feel disempowered by this disconnection, as it denies them a sense that they are valued, esteemed and cared for. As a consequence, their sense of security and self-confidence is diminished. At a deeper level, it may cause a 'biographical disruption' (Bury, 1982) similar to that experienced when one is living with a serious or chronic illness. As with ill individuals, Zintle and Mbulelo may ask: Why me? For them, the internal questioning may carry on along these lines: Why did my father abandon me? Why are my father's relatives not interested in me? Why am I so unlovable?

6.3.1 What about maternal uncles?

In Zintle's story above, a telling sign that there is also an absence of male figures from her father's side is her request for financial help for her 'matric farewell gown' from her paternal aunt. It is interesting to note that her mother has brothers who may have helped her in this area, yet she chose to seek help from her father's people. She spoke about her maternal uncles only in the light of the inheritance of her grandmother's house, discussed above (see 5.5.2. and 6.2). From this one can conclude that her uncles have not played the father-figure role that she desires, neither have they supported her financially.

This conclusion is confirmed by Zintle's grandmother, who said that neither of her two sons nor their sons supports her financially (see 5.6.2.2).

For the 21-year-old Palisa, her mother is the only surviving daughter. She had two sisters who are both dead. The only male figures in her life are her older brother and her 36-year-old cousin, Mbulelo.

6.3.2 An abusive male cousin

As indicated above, the only constant male in Palisa's life is her cousin, who was also brought up by the grandmother, 83-year-old Nomaindia. He still stays with Palisa and the grandmother. The two have had a very turbulent relationship through the years. In describing her childhood, for example, she spoke about the physical and verbal abuse from her cousin:

> It used to be very bad when my cousin came home from Port Elizabeth. He was a security guard and he used to drink a lot. Whenever he came home, he could get very angry at the slightest mistake, it could be the mess in the house or whatever, and then he would beat us up. He even used to beat up my grandmother.
>
> Palisa, 23 years old, Grahamstown

Palisa's cousin acknowledged this abuse, but he blamed it on alcohol:

> I know that alcohol is wrong. I was very troublesome. When I came from my drinking bouts I would shout at my family a lot. I would insult everyone and would talk non-stop. My grandmother never liked my drinking. The time I beat up my grandmother I was very drunk. I could not even remember why and that I had beaten her up. After this I felt very remorseful and I went to a Sangoma [traditional healer] to find out what was wrong with me [this is rather a significant acknowledgement as his grandmother and aunt were in the next room and they could hear what was being said in the interview].
>
> Mbulelo, 36 years old, Grahamstown

According to him, the 'one' occasion that he physically abused his grandmother "stopped me in the track and I promised never to lay a hand on my grandmother" (Mbulelo, 36 years old, Grahamstown). However, Palisa says that he is still abusive, even though he claims to have changed. Palisa's brother (see Appendix VI), who does not stay with them, also confirmed that his grandmother is still being abused by Mbulelo, Palisa and his 46-year-old mother, Ntombi. This information was communicated to us when Mrs Mcuba (Manager of GHDF and translator in this study) explored the ‘pension story’. The grandmother’s old pension grant is controlled by Palisa’s brother who does not stay in their house. This has brought conflict in this household (see 5.5.2.2). Palisa also blames her cousin for causing her to run away from home and for her horrible life. When asked if she is resentful towards her mother or grandmother for the way her life is, she said:

> I don’t blame my mother and my grandmother because I can see that my grandmother is being influenced by this one [Mbulelo] who has just returned from the hospital. So I don’t blame her either because she is also scared of him. I only blame my cousin.
>
> Palisa, 23 years old, Grahamstown

However, her reason for running away is not supported by her mother and grandmother, including Mbulelo. They all said that Palisa’s aggression and alcohol abuse is uncontrollable, to the extent that they have reported her to the police on a number of occasions. As mentioned above, her brother also talked about her alcohol abuse and aggression towards their mother and grandmother.

An insightful indication of Palisa’s bitterness towards Mbulelo is that she never once mentioned him by name through out the interview. She simply referred to him as ‘my cousin’, ‘this one’, ‘him’, ‘he’, and she described him as: “He is the son of our late aunt, my mother’s sister” (Palisa, 21 years old).

6.4 Work-related male domination

The dynamics involved in the phenomenon of patriarchy on the farm for the women in this study is well articulated by the eloquent grandmother, 77-year-old Nonceba. The following narrative is a response to the question on her feelings regarding her family’s eviction from the farm on which they had previously worked: ‘How do you feel about the way the farmer treated you and your husband?’:

> Yewh! It is a long and complicated range of feelings. I had a good working relationship with the farmer and I only used to be employed as a

> seasonal worker. I was a good worker as a result I made more money than the other seasonal workers. This made me unpopular amongst my co-workers. One of my husband’s sons from a girlfriend came to work on the farm. By this time my husband had stopped working due to poor health. One day the farmer came and told us that my stepson had stolen some property from him. To be fair to the farmer, my stepson was indeed stealing things from the farm and he wanted to move out of our home so that we couldn’t see what he stole. The farmer’s son was not as forgiving as his father, and this stealing business soured my working relationship with him. The farmer’s son was the one who was in charge of us. During Christmas we used to receive food parcels and a little bit extra money. However, the Christmas after the stealing story, I was only given half of what was due to me. The farmer’s son told me that was because my husband was no longer working for him and yet he was staying on the farm, the other half of my pay and food parcel were taken as compensation. Another reason he used was that my stepson had stolen from them. This was his way of getting back at us. After this, my stepson was chased and he went to look for work at the mines in Gauteng. This move however, brought further complications for us, because it meant that there was no male working at the farm from our household. This was a requirement for being entitled to a farm house. Casual workers or female employees did not have this privilege. In our house only my two daughters and I used to do seasonal work. This was used as reason for us to move and the farmer’s son was relentless in carrying out the eviction. My pleas to be allowed to stay until I got a place fell on deaf ears. I told him that since my husband was ill and I was working there was no time to look for a house. His answer was that he was no longer prepared to look after people – males – who were not employed by him. It was very difficult, actually impossible for my daughters and I to look for employment on another farm, as practically all framers preferred male to female workers. Women were only used as seasonal workers and as I mentioned earlier I could not be given permission to stay on the farm. Another reason the farmer was adamant that we move out of his place was that my husband was due to start receiving a disability grant and he knew that we wouldn’t be entirely dependent on him, but that we could only stay on his property and use up space/accommodation for prospective workers. My daughters refused to move to Port Alfred to stay with my relatives when I suggested it. They said that their father would be shunned and ill-treated by my relatives as he was not working. They would see him as a burden, because he had not yet started getting the disability grant.
>
> Nonceba, 77 years old, Grahamstown

In Nonceba’s narrative, a number of gender-based inequalities in farm employment emerge:

- Women were employed as seasonal workers.

- Deduction of bonuses and food parcels from female employees when their men had problems with the farmer.
- Women, as seasonal workers, were not entitled to housing on the farm.
- Eviction of the family from the farm when a male worker could no longer work. In Nonceba's case, the reasons for eviction were the loss of employment of her stepson due to theft and her husband's illness.
- Nearly all farmers preferred male employees above females.

From this simple narration of the relationship between the farmer and Nonceba's family, one sees the sophistication in her analysis of the gender dynamics at play in this interaction. She may not have the benefit of a systematic feminist's theoretical framework to guide her interpretation, yet she provides us with interconnections of patriarchal domination, both at work and in her home. Furthermore, she goes beyond the farmer's treatment by speaking about the 'complications' that her stepson brought to their lives. By so doing, she highlights the injustice suffered by women who are expected to look after a husband's children from 'girlfriends'. This is in addition to the emotional pain and suffering inherent in dealing with a promiscuous husband.

Nonceba later spoke about other problems that her stepson inflicted on her. He came back to stay in her home after a medical retrenchment in one of the Gauteng (Johannesburg, South Africa) mining companies. He had his legs amputated and was nursed by her, until his death. This was unsolicited information, which, as discussed in section 4.2.1, demanded to be included even if it seemed irrelevant at the time. These unsolicited bits of information or 'digressions', as qualitative, especially narrative researchers have recognised, provide a holistic understanding of the study participants (Riessman, 2003: 331). In Nonceba's perspective, this unsolicited information about the stepson adds coherence to her story on patriarchal domination in her home and at work on the farm. The following narrative further shows the taken-for-granted patriarchal attitude that men and society hold towards women**.** Following the in-depth interviewing flexibility (4.2.1), I include this narrative in this section as it has relevance to the reading and understanding of domestic patriarchy in Nonceba's life story:

> Oh, let me tell you something about that stepson of mine, who was partly responsible to our being evicted from the farm. He came back from Gauteng suffering from all sorts of diseases, and one of the things that troubled him the most were his legs. The doctor finally amputated both his legs because they couldn’t cure them. He started using the chair, by then he was staying with one of his brothers. This brother of his used to manage his terminal benefits money, but he (the brother) squandered the money and he was left destitute. His relatives from his mother’s side decided to bring him to my place because they told him that this is where he belonged. They told him that the house had been his father’s and as such he had a right to stay with us. I had no choice but to take him in. His health deteriorated and I knew that we were going to have problems when he died, because he had no funeral plan. I decided to take out a funeral insurance policy in his name. When he passed away, I used the funeral cover to buy the coffin and some of my own money because the insurance money was not enough.
>
> Nonceba, 77 years old, Grahamstown

A significant indication of male domination is the manner in which Nonceba’s stepson is lumped on her, regardless of her feelings on the issue. The taken-for-granted assumption that sons belong in their father’s home is used as justification for burdening Nonceba with the care and ultimate burial responsibilities of her stepson. Nonceba is thus silenced and expected to care for a son, whose very existence had been a cause of suffering, namely being a child of her husband’s girlfriend and causing her family’s eviction from the farm. To this, add the emotional and physical suffering inherent in caring for an adult son, who later becomes physically dependent on others, particularly Nonceba. Compounding all this suffering is the chronic poverty in Nonceba’s household, (discussed in Chapter 5).

6.5 Concluding comments

In this chapter, I have explored the patriarchal lived experiences of the women, starting with the ‘lobola’ marriages of the grandmothers. A common theme running through the two marriages is the reversal of roles. That is, both grandmothers were the main breadwinners. In this role, as financial and emotional supporters to their children and grandchildren, including their husbands, they encountered suffering. As 77-year-old Nonceba poignantly speaks of her life trajectory, “now even this poor eyesight is a result of the journey I have travelled". In the grandmothers' married stories, one sees the unfair burdening of household responsibilities on the women couched in lobola and other patriarchal norms.

Their married narratives echo those of the grandmothers in Gulati and Bagchi's (2005) collection of three generations of Indian women's stories. In this book, *A space of her own: personal narratives of twelve women,* nearly all the twelve grandmothers are depicted by their liberated and educated granddaughters (authors of the twelve narratives) as being thoroughly dominated in their marriages. In their stories, one finds a chilling similarity with what Nonceba said of her 'horrible' marriage. For her, like the Indian grandmothers, the worst was the helplessness felt in their oppressive lobola and dowry marriages. Being a married, paid-for woman (lobola), means that she was helpless in seeking redress for the physical and verbal abuse suffered under the hand of her husband. Thus marriage for Nonceba was experienced as a culturally sanctioned trap, in which her selfhood was silenced. Like her Indian counterparts and 83-year-old Nomaindia, she was "diminished and constrained by gender" (Gulati & Bagchi, 2005: 12). Whereas Nonceba was mostly constrained by gender, Nomaindia is silenced by her womanhood, wifehood, motherhood and grandmother-hood. The earlier discussed passive demeanour that Nomaindia displayed throughout the study, in speech and body language, shows a resignation that is born of an acceptance of one's subservient social position as ordained by God (see 5.4).

There is a significant difference between the stories in the above-cited Indian narratives and those of the women in this study. In the former, the succeeding generations were motivated by the grandmother's and mother's stories, and sought to re-order their predictable gendered biographical trajectories. Testimony to this drastic change in their personhood is the fact that all the twelve contributors, that is, the granddaughters, became accomplished academics and gender activists. This remarkable phenomenon is not repeated in the case of the granddaughters in this study. For them, the chronic poverty and its effects, passed on through the generations, is a major obstacle. This includes the gender oppression of their mothers and grandmothers, which for the granddaughters, expresses itself amongst others in the absent fathers.

CHAPTER 7
A CONCLUDING REFLECTION

7.1 Introduction

A major aim of sociological studies is to understand and explain the underlying taken-for-granted assumptions that structure the social world. In qualitative sociology the focus is on understanding social phenomena, while in the positivist tradition (quantitative) it is on explaining. Phenomenology, a theoretical framework used in this study, focuses on how individuals make sense of the world by categorising it. The process of meaning-making and categorisation is subjective, but intersubjectively created or informed. Consequently, the aim in this study was to understand how the two sets of three generations of black South African women living in poverty and affected by HIV/AIDS see themselves in relation to each other. The goal was to explore how they make sense of their HIV/AIDS experiences in light of their generational poverty. In the two following sections I reflect on the three themes of chronic poverty, HIV/AIDS and patriarchy from the study participants' perspectives. Finally, I reflect on the methodology of the study, by discussing the strengths and weakness of, for example, the research design.

7.2 On the women's experiences of generational poverty and HIV/AIDS

As indicated a number of times in the thesis, the core theme in the life stories of the six women is generational poverty. As I listened to the women's narratives during the interviews and observed the abject living conditions, it became apparent that the study topic of 'HIV/AIDS experiences' would be overshadowed by the experiences of chronic poverty. With the exception of 48-year-old Lulama, who is living with AIDS, the five participating women privileged their experiences of poverty above the effects of HIV/AIDS. Lulama's mother, the 77-year-old Nonceba, eloquently weaves her experiences of her two daughters' HIV/AIDS stories into other yarns and threads that arise from her lifelong experiences of poverty. This grandmother, as earlier mentioned, gave a sophisticated account and interpretation of her lived experiences grounded in poverty. For example, she provides a sociological analysis of her ill-health by contextualising some of the causes in her living conditions and in her relationships with her family. In summing up her life story, she equates her biographical history to her ill-health "now even this poor eyesight is a result of the journey I have travelled" (Nonceba, 77 years old).

Another example of how poverty is larger than HIV/AIDS in these two households is found in 21-year-old Palisa's story. This third generation woman explicitly privileged her family's poverty narrative. As pointed out earlier, Palisa was diagnosed HIV-positive in March 2005. She and her family have yet to experience what 48-year-old Lulama living with full blown AIDS and her family are going through. Thus one can understand and appreciate her bias in favouring her family's poverty over her HIV status when telling us her story. However, we must not lose sight of her position, that of an 'insider' in this interpretation. Palisa's reality as told in her own words is that being HIV-positive worries her, but that she is "angry. I am angry at my family". Directing anger at her family, not her HIV-positive status, is her way of articulating the household's dire condition. In a similar vein, she pins down her lack of desire to have children on her family's poverty and not her HIV-positive status: "I have struggled all my life. I can not afford to look after a child. Nobody can help me do this" (Palisa, 21 years old).

As most of the discussed narratives in Chapters 5 and 6 illustrate, the women's stories confirm a common research finding among poor women infected with and affected by HIV/AIDS. The finding is that chronic poverty is more threatening to these women than the risk and reality of HIV/AIDS (Baylies & Bujra, 2000; Ciambrone, 2001; ICW, 2004; Steinberg *et al.*, 2002; UNAIDS, 2004; WHO, 2002). However, there is an exception in the current study. For the 48-year-old Lulama, the reality of AIDS has disrupted her lifeworld similar to a 'biographical disruption' (Bury, 1982) as it is experienced by some wealthy individuals living with chronic illnesses. As the reviewed literature in Chapter 3 shows, her underlying existential assumptions that she held about herself and her lifeworld were thrown into disarray when she and her youngest daughter tested HIV-positive. The arrival of HIV/AIDS in her life was initially experienced as an unbearable event and led to her attempted suicide. The emotional suffering that she was already experiencing in nursing her sickly child was compounded by the social stigma attached to AIDS. For her, this expressed itself in the form of insults from her sisters and some individuals in her community. This in part explains why the double burden of AIDS, for herself and her youngest daughter, has superseded the experiences of her family's daily grind of poverty.

Lulama's story sensitises us to a phenomenological tenet, that of 'bracketing' our preconceived ideas about the study participants. In this case, I was forced to bracket my common sense knowledge, which was backed by the literature reviewed in Chapters 1, 2 and 3, that is, women living in poverty and infected with HIV/AIDS do not necessarily experience a 'biographical disruption' (Bury, 1982) or a 'loss of self' (Charmaz, 1983). In spite of this, most of what Lulama communicated, both verbally and in her body language, confirms a disruption in the essence of who she was before HIV/AIDS. This disruption includes, among others, her relationships with her mother and the participating daughter. She spoke about the pain she experiences in the reversal of roles between herself and her mother. As the eldest daughter, she is expected to care for her aged mother, who also has her own medical problems. And yet, it is her mother who nurses her whenever she is suffering from AIDS-related illnesses. She equally spoke about the pain and sadness that she experiences at the way her illness affects her children, especially her daughter with AIDS. She continues to blame herself for infecting her with HIV. She also expressed sadness at her inability to 'control' who will die first between herself and her daughter: "My wish and prayer to God is that he takes her first or that she becomes ill first so that I can nurse and be there for her".

In spite of Lulama's biographical disruption due to AIDS, her mother and daughter focus their stories on the family's lifelong poverty. Their stories are similar to those of the other set of grandmother, mother and daughter. Thus one can conclude that these women epitomise the Ugandan adage that poverty "passes from one generation to another as if the offspring sucks it from the mother's breast" (Group of disabled Ugandan women in CPRC, 2004-05: 3). Both grandmothers, the first generation in this trio, talked about their mother's poverty. One grandmother's mother died when she (grandmother) was a baby. As a result she was brought up by an aunt, whose poverty is evident in 77-year-old Nonceba's recalled childhood stories. She spoke about the suffering in her childhood that alludes to the aunt's household poverty, and may explain the harsh treatment inflicted on her by her aunt. The other grandmother explicitly talked about her mother's desperate poverty and her desire to look after her. These two stories continue this pattern of mother-to-mother poverty transmission. Like Lulama's human immunology virus which may have been passed on to her daughter through breast feeding, analogously, so has the first two generations of women 'breastfed their poverty to their daughters'.

Another observation from other studies that is evident in these women's life stories is that HIV/AIDS is the tipping point from poverty to destitution (Steinberg *et al*., 2002; WHO, 2002). In both households, the only stable sources of income are the two grandmother's old age social grants. At the time of the interviews, Lulama and her daughter were receiving disability grants given to some AIDS patients. These grants, as noted earlier, are conditional. Significantly this contribution to the household's income is minimal. Both households' aggregate incomes are inadequate for the massive needs in these families. In 77-year-old Nonceba's household, a total of R2 340.00 per month feeds and maintains seven people, while R780.00 per month is expected to feed and maintain 83-year-old Nomaindia's family of four. A grim suggestion is that these two households are one death away from destitution, if no other means of generating household income is expeditiously found.

7.3 On patriarchy

As the rhetorical question in Chapter 6's title suggests, there is a visible absence of men in the lives of the women. There are only two male figures in both households, a grandson in each. In spite of this, the six women have experienced and continue to experience male domination. I make use of Walby's (1990) analysis of practical patriarchal domination, discussed in Chapter 1, in my reflection on the participants' gendered social positions and how this affects their lifeworlds. Walby (1990) proposes six structures that help to maintain male domination and restrict women in different aspects of their lived experiences:

1. The first structure is the **patriarchal mode of production.** Walby (1990), like other feminists, argues that patriarchal production relations in the household mean an expropriation of the women's domestic labour by their husbands and partners (Walby, 1990: 61). Patriarchal expropriation is evident in the two grandmothers' marital narratives discussed in section 6.2. Their domestic labour was thoroughly exploited by their husbands. Once again, I draw on the story of 77-year-old Nonceba, as it provides a detailed account of the day-to-day varied forms of her domestic oppression. She portrays her husband as a drunkard who never provided adequately for the needs of his family, and she also said that he constantly slept out. This means that not only was he financially unsupportive, but he was usually incapable (slept out) of helping out with household chores. This summation of his negative behaviour towards his wife and family is confirmed by Nonceba. She spoke about how she built their present home on her own: "I managed to build a mud house of our own, because my husband never helped. He just used to lie down and do nothing" (Nonceba, 77 years old). Based on this, one can assume that Nonceba's husband did not provide building materials because he was simply 'lying down and doing nothing'.

   Nonceba's contemporary, 83-year-old Nomaindia, embodies the feminist idea that women internalise the pervasive patriarchal norms that couch women's domination. She, contrary to Nonceba, portrayed her husband as a 'stable man, who liked to stay at home and never drank'. There is a contradiction in this 'stable' painting: Nomaindia spoke of being the breadwinner throughout her life. An indication of how Nomaindia's domestic labour was also expropriated by her husband is when she spoke about her shattered dream of helping her mother after she got married: "I saw myself getting married here in Grahamstown, although I was not from here and all my dreams were shattered because I couldn't help my mother any more". As this statement is in hindsight, it points to a marriage in which she was a major provider in her household, and as such she was unable to look after her mother. Her mother was still residing on the farm, while Nomaindia stayed in Grahamstown with her husband and her children. By painting a loving picture of her late husband, she is in effect silencing herself and sanctioning domestic male domination. Nomaindia's 'culture of silence' echoes the stories of the Indian grandmothers and mothers in the earlier cited book by Leela Gulati and Jasodhara Bagchi. These women, like Nomaindia, learnt to internalise their marital pain because of cultural practices inherent in lobola and dowry marriages, as discussed earlier. As Arlie Hochschild concludes on one of the Indian women's narrative on her experiences of domestic patriarchy, Nomaindia like the Indian woman was "paradoxically, forced into an authorship of her own suffering" (Hochschild, 2005 in Gulati & Bagchi, 2005: 258).

2. **The patriarchal relations in paid work:** Walby (1990) sees this structure in terms of patriarchal relations within paid work. For Walby, the focus is on the varied forms of patriarchal closure within waged labour that exclude women from better forms of work and segregate them into the worse jobs which are deemed to be less skilled (1990: 25-59). Three of the four women in this study who belong to the first two generations said little or nothing about their experiences as waged workers. They were employed as domestic workers and seasonal farm labourers. A major reason is that they only had rudimentary formal education and this negatively affected their access to an already limited apartheid labour market. The two daughters, that is, the second generation of women, are still doubly disadvantaged by this lack of education and the present situation of limited jobs in the new South Africa. For 48-year-old Lulama, having AIDS further limits her chances of getting employed.

   The only woman who gave a detailed account of her farm work experiences is 77-year-old Nonceba. Her narrative in section 6.4 demonstrates a sophisticated analysis of gender dynamics that were prevalent in farm employment. Ironically, she is the only woman in this study who has never been to school, and yet she possesses a ‘natural literacy’ in reading and commenting on social issues. Her analyses and interpretation of her lived experiences on the three broad themes of this study (poverty, HIV/AIDS and gender) was done collectively most of the time. She possesses an insightful awareness of the general working conditions that negatively affected women as seasonal workers on the farm. The summarised gender based inequalities in farm employment in section 6.4 emerged from her narrative on work experience. She tells us how she, as a woman, was unfairly sidelined by her employer in favour of the already marginalised black male farm workers. She spoke about her experiences as a seasonal worker and the insecurities that were inherent in this position. A major insecurity was that female workers, whose husbands were not employed, were not entitled to being housed on the farm. For Nonceba, this expressed itself in the eviction of her family from the farm, when her husband and stepson stopped work. Her husband stopped work because of his failing health, while her stepson was dismissed because he stole from the farmer. This effectively left only Nonceba and her two daughters as workers in their household.

3. **The patriarchal relations in the state:** In this structure, Walby argues that the state is patriarchal as well as being capitalist and racist. She asserts that the state has a systemic bias towards patriarchal interests in its policies and actions. Men monopolise positions of political power (1990: 150-172). The women’s stories on patriarchy as it is practised by the state are mainly expressed through their day-to-day lived experiences. Even the eloquent 77-year-old Nonceba only alluded to this form of patriarchy in her narratives. These women’s energies were and are still focused on immediate survival needs. However, by virtue of the colour of their skin and their gender, these women experienced the consequences of this structure of patriarchy. Like their counterparts in the Barrett *et al.* (1985) study cited in Chapter 1, they experienced the effects of the racist and capitalist policies in the apartheid South Africa. The black women in the Barret study spoke about their lived experiences arising from patriarchal state policies such as the influx control and pass laws. The women in this study, as I have just noted, experienced

the consequences of influx control and pass laws, because of who they are – black women.

The state-sanctioned racist policies have been constitutionally stopped and the new government is attempting to reverse the plight of the blacks, including black women. However, as Desmond Tutu and others comment, “apartheid has left a ghastly legacy” (cited in Harker, 1994: 208). Women, as the stories of the three generations of women in the present study show, continue to be at the bottom of the capitalist new South Africa. As I mentioned in Chapter 1, the high number of gender-based organisations points to the dire need to uplift women, specifically the worst marginalised black women in black townships and rural areas. In addition, the present government, like its predecessor, continues to be male-dominated. This means that its policies are still to a large extent gender-insensitive. One must, however, acknowledge the positive changes in the present political leadership. There is a deliberate move to empower women by appointing them in top political leadership positions – e.g. Phumzile Mlambo-Ngcuka as the country’s first female Vice-President, Nkosazana Dlamini-Zuma as Foreign Affairs Minister, Manto Tshabalala-Msimang as Minister of Health, Naledi Pandor as Minister of Education etc. The discussion in the following patriarchal structure is a typical example of the state’s insensitivity to women’s experience of male domination.

4. **Male violence:** Walby (1990) sees male violence as constituting a structure, despite its apparently individualistic and diverse form. Male violence is systematically condoned and legitimated by the state’s refusal to intervene against it, except in exceptional instances. According to the feminists, the practices of rape, wife-beating and sexual harassment, among others, are too private in their practice to be part of the state itself (Walby, 1990: 128-149). Through the well-articulated marital narrative of 77-year-old Nonceba, we see how domestic violence is sanctioned by patriarchy – in this case through the oppressive tradition of lobola marriages. She never mentioned whether she had ever reported her

husband to the police, or whether her neighbours intervened. She only mentioned that a landlord had once expressed shock at the level of battering she had to endure from her husband. From this silence, one can conclude that the police (state) or neighbours were reluctant to intervene against her abuse. To add to her helplessness, she was unable to seek intervention from her family as her marriage was couched in the lobola norms. As the feminists argue, her suffering was normalised through patriarchy and solidified in the lack of help from the state services and her family.

The story of 21-year-old Palisa demonstrates male violence as it is experienced by women, not only from their husbands but also from their male relatives. She is physically abused by her male cousin (see 6.3.2). Beyond this physical violence, she is also emotionally affected by the absence of her father and the lack of financial support. In this regard of an absent father, she has similar experiences with her contemporary, 23-year-old Zintle. Zintle spoke at length about her emotional pain regarding her lack of relationship with her late father (see 6.3). She attributed his absence from her life mainly to his womanising and his many children. Her father's behaviour, like that of her grandfather (Nonceba's husband) was sanctioned by patriarchy. In her grandmother's case, in addition to the emotional pain of dealing with an unfaithful husband, she was forced to nurse a stepson. This is the same stepson who had caused Nonceba's family's eviction from the farm (see 6.4). Zintle's mother, 48-year-old Lulama, also talked about the emotional spousal abuse. When Lulama tested HIV-positive, her then husband refused to accept her result. One can assume that this denial must have come with insults and accusations. In addition he hid his own HIV-positive status from her and only disclosed it when he learnt that she was receiving an AIDS grant.

5. **The patriarchal relations in sexuality:** Patriarchal relations in sexuality constitute a fifth structure. Compulsory heterosexuality and sexual double standards are two of the key forms of this structure (Walby, 1990: 109-127). For the women in this study, sexual double standards come in the form of the

society's attitude towards the men's extramarital affairs. The story of 77-year-old Nonceba provides a good example. Her husband had many children from different women. She, on the other hand, was expected to have children only from her husband. This tells us that she had internalised the 'patriarchically' informed notion that it is a man's privilege to have extramarital sexual relationships. Her daughter, 48-year-old Lulama, has a similar story – only she divorced her husband. This shows a transformation in the succeeding generation of women in this study. Like Lulama, 46-year-old Ntombi also divorced her husband and has had different relationships with men other than her former husband. This liberation however comes at a price. These two daughters' sexual behaviour is socially seen as immoral. In the case of Lulama, it is possible that the insults from her sisters and the community when she tested HIV-positive, involved her being labelled as a prostitute. Her husband may also have blamed her for infecting him and the child. This assumption is confirmed by the stories of HIV-positive women in other studies (Baylies & Bujra, 2000; Ciambrone, 2001; ICW, 2004; Steinberg *et al*., 2002; UNAIDS, 2004; WHO, 2002).

6. **The patriarchal relations in cultural institutions:** Patriarchal cultural institutions complete Walby's (1990) six structures. For Walby, cultural institutions are significant for the generation of a variety of gender-differentiated forms of subjectivity. In Walby and other feminists' view, this structure is composed of a set of institutions which create the representation of women within a patriarchal gaze in a variety of arenas, such as religion, education and the media (1990: 90-108). For the women in this study, this includes the traditional customs such as lobola (bride price), where a woman is seen as the man's 'property'.

The above structures, as I stated in Chapter 1, are interlinked and have causal effects on each other. The aim of using Walby's (1990) six structures is to show how pervasive patriarchy is in the lifeworlds of the three generations of women. Furthermore, it enhances our understanding of how difficult it is for the women to unshackle themselves from the burden of patriarchy. This is exemplified in 77-

> year-old Nonceba's life story, particularly her marital narrative. Speaking on her spousal abuse, she lamented: "What saddened me the most is that I was powerless in doing anything and I had nowhere to run to. If I went back to my aunt's home, they would have sent me back because the custom was that once 'lobola' is paid one no longer belonged to her family. She was the husband's 'property'. Once one is married one has to endure all the hardships that came with being married – good and bad; battered and loved; everything" (Nonceba, 77 years old).

The reflection in the above two sections shows how the HIV/AIDS stories of the women are intricately interwoven with their other lived experiences. As stated earlier, HIV/AIDS is one among the many dire situations that these women have to deal with on a daily basis. As I questioned in the conclusion to Chapter 3: How can we then tease out particular research concerns such as a 'biographical disruption' (Bury, 1992) due to AIDS? Alternatively, how can we simply focus on the consequences of HIV/AIDS on the family members, in this case the two grandmothers, mothers and daughters? What do we do about their poverty and patriarchal experiences? This study shows that the three generations of women experience HIV/AIDS on a continuum involving chronic poverty on one side and patriarchal dictates on the other. This includes the relationships to each other, and their own biographical histories. For the latter, the memories of their past experiences inform and shape their present understanding and interpretations of their lifeworlds. Their stories move from one end to the other, and as such all three themes need to be included in our attempt to understand their HIV/AIDS lived experiences.

7.4 On the study methodology

In this final discussion, I reflect on the strengths and weaknesses of this study's methodology. By using phenomenology as the major theoretical and methodological framework, I have privileged the women's own interpretations of their lifeworlds. The focus was on the meanings that they attached to their recalled lived experiences and how this informed their present situations and identities. As the discussed narratives in Chapters 5 and 6 show, the in-depth interviews produced rich data that give us insight into the lifeworlds of these women. The life story narrative enables us to understand how HIV/AIDS is experienced by the women, not in isolation, but together with their realities of poverty and patriarchy. Their HIVAIDS stories can only be understood by looking at the complex interactions of their individual life narratives and those of their grandmothers', their mothers' and their daughters'. Thus as Farmer (1997: 262) observes, the women's "gritty details of biography" enhanced our understanding of their suffering. This understanding is limited in studies which use quantitative methodologies and whose focus is on statistics and not on how the participants experience the phenomenon under study.

There are however concerns and weaknesses in this study's methodology. In addition to the issues discussed in Chapter 4, a major concern is subjectivity. All the recalled experiences are each individual woman's subjective interpretation of past events. While attempts were made to confirm or clarify certain narratives by asking the other participating women, these clarifications were also subjective constructions. For this reason the women's testimonies need to be read objectively and contextually. By this, I mean a reading that is mindful of how the recalled narratives are affected by the women's current lifeworlds, poor memory in case of one grandmother, and the 'universal' need to tell a socially desirable story. For example, the grandmothers' stories within the study context (during the interviews) were shaped to highlight what they perceived as problem areas.

Another important concern and weakness is that the prolonged and intimate engagement with the women led to some negative emotional experiences, for both the women and myself. I was emotionally distressed by the women's stories. Most of what they were speaking about was solidified in their observable abject living conditions. As I mentioned in Chapter 4 when reflecting on my role as a researcher, this left me feeling like I was simply "holidaying on people's [*the women's*] misery" (McRobbie, 1992 in Letherby, 2000: 101, parentheses and italics added). For the women, the long repeated interviews may have raised false expectations about the study's outcome. This was confirmed by the grandmother who is constantly left alone by her daughter and grandchildren. After our concluding interview, she expressed sadness and asked Mrs Mcuba, the translator, why I couldn’t continue to visit her. For her, our ‘academic’ relationship had taken on a different meaning. In her mind I was categorised in a similar manner as Mrs Mcuba, the manager of GHDF, a CBO that provides food parcels and emotional support to her household.

In conclusion I hope that this study contributes to our understanding of how these six women living on the fringes of society are experiencing HIV/AIDS. This study adds to the much needed collection of ‘insider’ stories, especially the narratives of the marginalised poor women.

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Appendix I Interview guide

Preliminaries

1. Introduction
2. Explain the purpose and nature of the study
3. Ethical issues:
    - Obtain verbal consent to partake in study
    - Confidentiality – use of pseudonyms in report to preserve anonymity
    - Tell them the interview will be tape-recorded and then transcribed
    - Explain that this is an academic research and that no financial gain will arise from their stories for them

Guiding themes of the interview questions

1. Biographical information, e.g. date and place of birth
2. Childhood memories
3. How women see their identity in relation to each other.
4. Specific questions for the HIV-positive individual:
    - What were your initial feelings when you tested HIV-positive?
    - What were your feelings about AIDS before you knew you had it? Were you afraid that you would get it?
    - What are your feelings about dying young?
    - What worries you the most about your present situation?
5. The impact of HIV/AIDS on the grandmothers, mothers and daughters.

The closing

I need to maintain the tone set throughout the interview – friendly and courteous – and I need to be brief but not abrupt in ending off interview sessions. Thank the women for their time and tell them that I will be calling on them at a later date to build on or clarify issues from the previous interview or from other family member's interviews.

Appendix II The interview transcript on Zintle's unexpected marriage

When I learnt that Zintle had got married I decided to conduct an interview on this issue to clarify concerns that had an impact on what she had earlier told us. I wondered whether she had been telling us a 'socially desirable' version of her role as 'care-giver' to her mother and 'substitute mother'. How could she have failed to tell us how serious she was with her boyfriend? I was mindful that she may very well have been taking the marriage as a platform to secure her siblings' future, if one takes into account all that she and her mother as well as grandmother said regarding the possibility that her uncle may evict them from the house when her mother and grandmother dies. This is pure speculation on my part, but I am hoping on the one hand that this is the case, otherwise it may cast a huge shadow on all that Zintle told us. On the other hand, it may give me and the readers insight into how desperately poor people make major life decisions based on what is ideal for them and not what is socially acceptable.

Interviewer: Last time we spoke to you, you did indicate that you have a boyfriend, but you did not tell us how close or how serious your relationship was. It was a great surprise to learn that you had got married. You spoke at length of your desire to help your family and that you were already acting as a mother to your younger siblings and care-giver to your mother. Is marriage going to interfere with this area of your life?

Zintle: My marriage came as a surprise to me as well. The marriage has not interfered with my care-giving role. This is because my marital home is very close by and I come over to help my mother and sister, and others in the family every day. There are no changes in my life as far as this role is concerned.

Grandmother: Let me say something about this marriage. Zintle's in-laws were told about her job in this house, so our consent to her marriage was on condition that she continues to look after her mother and sister. They agreed [According to the Xhosa tradition, a newly wed woman (makhoti) is supposed to do most of the house chores in the in-laws' home. Furthermore, when lobola – bride price – has been paid, a makhoti is not expected to frequently go to her parental home].

Interviewer: Does your husband work?

Zintle: Yes, he works at a dry cleaning company, in town.

Interviewer: In a previous interview, you had mentioned a desire to improve your matric subjects so that you could study for a social work qualification. Are you still interested in pursuing this dream?

Zintle: [Laughs] First, as a makhoti wearing this type of clothes, I will not be allowed to go to school. I have to ask permission from my in-laws to do this. Second, my husband’s salary is barely enough to see to our basic needs and those of his parents. But, given a chance I would love to do social work even if I am married.

Interviewer: Sorry Zintle, this is going to be a very personal question. You are fully educated on how HIV is transmitted. Did you and your husband have an AIDS test before you got married?

Zintle: Yes. I went on my own and then we both did a test. We are both HIV negative.

Interviewer: Do you want to have children?

Zintle: [Laughs] Yes, two.

Interviewer: In the interview with your mother, she mentioned that there are children in this household who receive grants. Who is it and what grants are they?

Zintle: It is only my young sister, Nozuko, who receives an HIV grant of R780.00.

Interviewer: How many grandchildren stay with your grandmother?

Zintle: Three.

Interviewer: Your grandmother mentioned earlier that two of Nosipho’s [her HIV-positive aunt] children are in Addo with one of your uncles. Are they just visiting or do they stay there?

Zintle: They stay there and they only come here during the holidays.

Interviewer: Thank you, Zintle. [I ended the interview, but we stayed on for a while to chat.]

A reflection on above interview session

This was the first occasion in all my interaction with Zintle that she seemed relaxed and happy. She was genuinely beaming and as evidenced in the above transcript, she laughed a lot. It is the only time that she laughed during the interviews. The above interview quelled my concerns about what she had told us in prior interviews.

Appendix III Nonceba's household (principal participants)

There are seven people living in this household in Joza. The main source of income is the grandmother's old age pension. Two daughters and a granddaughter are in the full blown stage of AIDS. There are two small houses on the property. The main house consists of two rooms – a bedroom for the mother and a largish room that is used as a sitting area, kitchen and bedroom. There is an extra room, but it is closed off from the main house as the daughter who occupies it constantly fights with her boyfriend, which disturbs others. The outside house is a single roomed apartment used as a sleeping area. The main house is in very bad condition structurally, as the roof leaks and water seeps through the floor when it rains. There is, however, a loving attempt at decorating the interior. A hanging on the wall immediately caught my attention. It has a shiny black background and silver writing in Xhosa which translates: "A home is home no matter the circumstances". This household has a homey feel to it compared to the Vukani household's cold and bare new house (see Appendix IV). However, both households make no attempt at beautifying the outside surroundings. Whilst the Vukani family's worn out furniture was draped in eclectic pieces of material, the Joza family have covered theirs in black garbage disposal bags. This is to keep the furniture clean and protect it from damage. Despite obvious poverty and the effects of HIV, this household is a lot 'happier' and less gloomy than the Vukani family. The neighbourhood is also much more vibrant than the new township of Vukani. Even though the Joza grandmother has more on her plate, she seemed more assertive and in control of her life than her counterpart. She is physically large and has a commanding presence, whereas the Vukani grandmother is small and withdrawn. She was very articulate in the interview and she is a good story teller, she made us feel her story. When she narrated the good childhood experiences she truly beamed. She was equally expressive when she talked about her present life circumstances. She showed great sorrow when narrating her feelings regarding her HIV-positive daughters and grandchild. She cried as she spoke about this particular area of her life. She is angry at God for giving her so much to deal with. However, she noted that there was a lesson to be leant in all her suffering and she is yet to find this out. The emotional expression was congruent with the narratives. Her daughter and granddaughter were equally expressive. They both showed great sadness, which were juxtaposed with joyful emotional expressions when speaking about ‘good’ times. For example, the daughter had a good laugh when she noted that she uses her HIV-positive status and ill-health as a means to get extra attention and love from her family. She said that sometimes she pretends to be very ill and lies in bed, when all she needs is some TLC (tender loving care).

Appendix IV Nomaindia's household

There are four people in this household in Vukani location – the grandmother, a daughter, a granddaughter and a grandson. At the time of the interview, the grandson had just discharged himself from Santa hospital, where he was undergoing TB treatment. He is living with AIDS and he is on ARV medication. At the initial interview we were told that the granddaughter, who is HIV-positive, had beaten up the grandmother and had moved out of the house temporarily. The grandson claimed this is the reason why he discharged himself from the hospital – to come and look after the grandmother and protect her from being abused by his cousin (the granddaughter). However, the granddaughter claimed that it is her cousin (the grandson) who abuses the grandmother and he is the reason she had left home. During the first interview, both grandmother and mother were not articulate and I put this down to the presence of the grandson. The grandmother appeared sad and had a docile demeanour about her. She hardly looked up when talking and rarely made eye contact.

This family has recently moved into a government-subsidised house in Vukani location. Vukani means "Wake-up!" According to them it is the best home they have ever lived in. They previously lived in tin shack dwellings and mud huts, around Grahamstown. These accommodations had very minimal council services – e.g. bucket collection and communal water supply. This new house is brick-built and has an inside toilet as well as a small sink in the kitchen. It has two bedrooms, with an open plan kitchen and sitting area. There are three couches in the lounge and a few kitchen utensils lined against the kitchen wall. There are no family photos or any form of decoration on the walls. The sofas are torn and different loose pieces of material are used to cover them. The house feels very cold and sombre. This house is situated on the last row of houses, which adds to its forlorn feel. The neighbourhood is surprisingly quiet for a high density housing estate. The only noise I could hear in the background was a rooster, and there were no people passing by.

Appendix V Mbulelo, 36 years old

Mbulelo (pseudonym) was born at a farm on the way to Port Alfred, on 6th August, 1970. When he was around six, his mother and grandmother moved to Grahamstown, and lived in Fingo village. His parents never got married, and he had no relationship with his father when he was growing up. He expressed anger at the fact that his father wanted to establish a relationship only when he was old and working. He was introduced to his half-brother and half-sister who, according to him, only want his money. On his mother's side, he had a young sister who died when she was six months old. He went to school and quit in standard eight (grade 10). The main reason was that his grandmother was the only one working and she could not afford to pay for all his school needs. His mother had once worked as a domestic and used to support him. However, her employers moved away from Grahamstown and she could not look for work elsewhere as she was badly injured when she was hit by a car. His mother died in 2004 from cancer of the throat. He was diagnosed with AIDS in 2005 and he is on ARV medication. He recently discharged himself from SANTA hospital where he was receiving TB treatment.

Appendix VI Sipho, Nomaindia’s other grandson

Sipho is Ntombi’s son – the one who looks after the grandmother’s pension funds. He occupies a big part of the narratives of the other family members in this particular household. We decided to talk to him so that he could verify some of the things that his mother, cousin and grandmother said about him. He agreed to talk to us, but we were unable to schedule an appropriate time. Mrs Mcuba agreed to get his side of the story and then tell me what he had to say.

Mrs Mcuba’s impressions

Mrs Mcuba sees some truth in Sipho’s version of the pension narrative. First, he proposed that a third party other than his mother or cousin takes over the responsibility of managing his grandmother’s pension. According to Mrs Mcuba, and I agree with this view, it shows that he is really concerned about his grandmother’s welfare, even though he is not entirely a good manager of the funds himself. The second reason is that he repeated the claims that he had earlier made about his mother and cousin in his initial interview with Mrs Mcuba. This was during the second interview when his mother was present. The mother kept quiet meaning she agreed with what he was saying. She (the mother) is a very assertive character and yet she appeared very docile and submissive when confronted with Sipho’s story about her behaviour.