An Experiential Study of Caregiving for HIV and AIDS Patients in the 'Pre-ARVs Era' in Lesotho

Submitted by

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Declaration

This thesis is my own work. I know that plagiarism is wrong. I have used the Harvard referencing style for in-text citation and list of references. Every significant contribution to, and quotation in this thesis from the works of other people has been cited and referenced accordingly.

Date: ***10th April 2007.***

Place: ***University of Cape Town.***

Signed: Signed by candidate

Dedication

To my late mother, 'M'e 'Makhakanya Alice Matebele, who showed me how to care; my father, Ntate Pohonyane Bernard Matebele, who showed me what it means to work in the name of care; my daughter Nate and my son Khabane, who gave me the opportunity to practise care.

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Stay blessed.

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Abstract

This thesis reports and discusses the findings from an investigation of the experiences of family caregivers who provided care at home for chronically and terminally ill family members diagnosed with HIV and AIDS in Lesotho prior to the introduction of publicly funded ARV treatment. The data were obtained through in-depth interviews with twenty-one family caregivers using in-depth interviews following the phenomenological approach. The interviewees were selected with the help of counsellors and nurses responsible for HIV and AIDS care and support in two hospitals in Lesotho.

From the interviews it emerged that most of the caregivers did not receive information pertaining to the HIV and AIDS condition of the people they were caring for or had cared for from either the patients or medical personnel. The few who did receive such information received it at the hospitals. This study contributes to understanding the world of informal care by using the ideas encapsulated in the *ethic of care* and *ubuntu* to identify the factors which were unique to HIV and AIDS home-based care and influenced the experiences of family caregivers in Lesotho. Caregiving was predominantly characterized by negative experiences but there were caregivers who despite the unpleasantness of seeing their loved ones ill and dying identified some pleasures and positives in their caring activities.

The experiences conveyed by the respondents and reported and discussed in the thesis indicate that the issue of confidentiality, the "minimum package of care", and de-medicalisation of HIV and AIDS care and rationing are significant issues requiring urgent discussion and policy (re)consideration. It is concluded that improved communication between the care-recipients, health care providers and family caregivers about the HIV diagnosis and prognosis as well as improved access to medical care are consistent with the *ethic of care* and *ubuntu* and these could influence caregiving experiences positively.

Key words: *Lesotho; HIV & AIDS; phenomenology; care ethic; ubuntu; confidentiality; the body; demedicalisation.*

CHAPTER ONE

BACKGROUND AND INTRODUCTION

Background

The advent of the human immuno-deficiency virus and Acquired Immune Deficiency Syndrome (HIV and AIDS) and the introduction of home-based care as part of the response to the care needs of the people who were ill due to the HIV infection changed the landscape of the health care system in Lesotho. The impact of the epidemic on the health care system certainly led to major changes in the location of care for people who had chronic illnesses. The home sphere instead of the hospitals became the main domain where care for HIV and AIDS patients took place. In addition, policy documents established new categories of care volunteers in the communities and families who were expected to take the responsibility of providing care for the chronically ill. They became known as community-home based caregivers and family caregivers, respectively. This was in addition to the cadre of village health workers (VHWs) under the primary health care (PHC) strategy even though there were overlaps. Of significance also was the recognition given to 'chronic illnesses' as a distinct category of health conditions used by planners and health workers to justify home-based care and gloss-over HIV and AIDS as the main reason for the structural changes in the organisation of health care in Lesotho. These were new emphases in a society that had increasingly become dependent on the hospitals for their health care – for both acute and chronic illnesses.

Biomedicine and hospitals were introduced in Africa during the colonial-missionary times in the nineteenth century. Colonialism, Christianity and biomedicine in Southern Africa were part of a single Western project to suppress African ways of life and introduce civilisation (Flint, 2001). At independence, the African states assumed the primary responsibility to provide health care to their citizens (Stock and Anyinam, 1992). In Lesotho the state continued its support for biomedicine, especially hospitals, and synergies with the Church led to the development of infrastructural networks and a health care system organized around hospitals. The main partner in this realm has been the organisation of faith institutions known as the Christian Health Association of Lesotho (CHAL).

Concurrently, there were serious attempts to decentralise health care and this was accompanied by civic participation in health issues. The Primary Health Care (PHC) approach, initiated in 1979 following the Alma Ata Declaration and revived through the *Bamako Initiative* which the government adopted in 1991 was designed to "empower communities to take control of their own health needs" (Ministry of Health, 1993: 41). The strategy was adopted to facilitate the values embodied in the then new ideology which promoted the participation of volunteering village health workers (VHW) and health centres (clinics) to provide health care services such that the dependence of the public on hospital outpatient departments could be reduced. The public health service system was organised according to eighteen health service areas (HSAs) and the focal unit of an HSA is a hospital. Ten of the HSA hospitals are owned by government and the rest by member organisations of CHAL. Furthermore, public health care is organised according to three levels: primary health care which is available through health centres and clinics, secondary level accessed through district hospitals and the CHAL institutions, and the tertiary level which consists of the only referral hospital located in the capital, Maseru – Queen Elizabeth II hospital. However, due to various constraints, especially the poor supply of drugs at the primary level, most people circumvent this level in favour of hospital facilities for both in- and out-patient care (Ministry of Health, 1993).

Poor coordination between the primary and the hospital levels concerning the outcome of referrals made from the former has been observed (Ministry of Health, 1993) but referrals by clinicians would usually be honoured and hospitalisation of the patients who were too ill as well as prescriptions were common medical responses during consultations. What is particularly interesting in the context of home-based care is that at community level, the VHWs did much of the disease surveillance work without inhibition and referred individuals for medical care on the basis of their own interpretation of the symptoms. In this way they constituted one of the pillars of the PHC strategy. There were health gains which were realised under this health system which relied on the collaboration of the voluntary and the formal sectors in the form of clinics at the primary level and a two-tier hospitals system. Therefore, it was reasonable when it became inevitable to adopt home-based care for people chronically ill from AIDS-related illness to expect that the strategy would benefit from community and family resources. The rationale for a policy shift which promoted the practice of home-based care in the new millennium in Lesotho was framed within the PHC strategy.

Private health care is mainly provided by general practitioners commonly known as private doctors, privately operated clinics which provide services to the middle class patients who avoid overcrowded public facilities which also tend to have a chronic problem of drugs shortage. Traditional doctors also provide vital services for various reasons: traditional belief systems link certain illnesses to factors outside the expertise of biomedicine, indigenous knowledge has been used to treat certain symptoms effectively and the service is readily available especially in the rural areas though it may be for people who afford the relatively high fees (Ministry of Health, 1993). But traditional medicine did not receive state financial support for a long time. In the 1990s attempts were made by some hospitals to collaborate with traditional doctors in the treatment of pulmonary tuberculosis and more recently in the area of HIV and AIDS. But the predominant goal has been to subjugate the traditional beliefs and practices which hamper the modernisation of health care in the country.

Consequently, the health care system which evolved in the last century was largely dependent on biomedicine and institutional care, especially hospitalisation. Perhaps TB treatment and maternal health among Basotho are two interesting areas that represent what may be seen as classic examples of a phenomenon referred to as the 'medicalisation' of life. Biomedicine used intensive public health programmes, including education and free treatment, to replace the cultural explanatory frame of reference which used the term *sejeso* for an illness believed to be caused by witchcraft and has the same symptoms as TB; chemotherapy, medical drugs and hospitalisation instead of traditional therapies such as induced vomiting were promoted and compliance encouraged. Special TB wards were established within the hospitals and TB treatment entailed six months, later reduced to three months of hospitalisation. With the introduction of direct observation therapy (DOT) the hospitalisation period further decreased to two weeks. Community members are encouraged to be vigilant and refer individuals who display suspicious symptoms.

Similarly, maternal reproductive health is pursued through the placement of pregnant women in hospitals where they are brought under constant clinical gaze. Women spend most of the pregnancy period dependent on the health care professionals for antenatal care and increasingly pregnancy and birthing are the activities of the different specialities within the medical profession; they are monitored using various levels of medical and technological interventions which are meant to diagnose and treat complications which threaten the survival of mothers and children. In 1990 more than 55 percent of females aged between 15 and 49 years were hospitalised for "normal delivery" (Ministry of Health, 1993), while about 60 percent of births occurred in hospitals and maternity centres with the help of skilled personnel (Bureau of Statistics, 2002).

It is noted that the health policy has been characterised by a strong emphasis on the supremacy of medicine in preventing and curing disease as well as its relevance in spheres of life which would not traditionally be defined medically, and institutional care was a norm. Mental health also continues to be provided through both short- and long-term institutionalisation. It is also noteworthy that in many aspects of life medicine improved the wellbeing of the population thus bolstering the view that medicine was an effective way of dealing with disease and illness. Seeking medical care and expecting hospitalisation are some of the entrenched practices among modern Basotho such that prior to the introduction of home-based care, most obituaries specified hospitals because family members would usually make attempts to transfer dying patients to the institutions. These practices give a picture of a society which had developed a culture of institutional care in which families depended on hospitals to provide care for both acute and chronic illnesses. These achievements were undermined by the HIV and AIDS epidemic because it reduced the capacity of the formal health care system to provide long-term hospital care thus making home-based care an inevitable and indisputable practice.

Further, home-based care was consistent with the policy shifts that occurred globally regarding health care provision whereby governments increasingly devolved the responsibility from institutions to communities. The spread of this practice in the developed countries was encouraged by the UN International Commission on Population and Quality of Life (ICPQL) which proposed deinstitutionalization of care in these countries; suggesting the adoption of primary care through community clinics, home-based programmes and preventive initiatives, as well as reducing expenditure on the curative high technology hospital-based model (ICPQL, 1996). Therefore, the changes in the approaches to health care in the developing countries such as Lesotho were influenced by both internal and external factors. Specifically, the reduction of government expenditure in the health sector occurred within the structural adjustment programme (SAP) framework; the result of which was restricted availability of and access to medical care (Ministry of Health, 1993). The political economy perspective sees the neo-liberal economic policies such as the SAP, imposed by the Western financial institutions on African societies since the 1980s, as responsible for declined public expenditure on the social sector (Mwanza, 1999). Therefore, the underlying reason for the shift towards home-based care should be understood within the context of the global order in which more governments in the developing countries opted for less state expenditure in health care and social services due to external pressure to rectify their balance of payments. Notwithstanding, there has been a tendency at policy level to argue that the resurgence of home-based care was in accordance with the core values of communal and family life in Africa. Various sentiments which resonate with broader traditional ideas such as the *ubuntu* philosophy and the virtue of family relationships were used to highlight the attractiveness of this approach in Africa where the family institution was initially portrayed as a resilient safety net in the AIDS crisis. However, the idea of the benevolent extended family and community in the care of HIV and AIDS patients could be largely speculative and may be a value based on the cherished past.

In Lesotho the first (AIDS) case was identified in 1986, in 1994 about 238 new cases were reported and AIDS had not yet reached epidemic proportions (Romero-Daza, 1994). But five years later, more that 3 500 new cases were reported (Government of Lesotho, 2002a) and Lesotho became one of the countries with the highest prevalence rates of HIV and AIDS in the world – estimated at 31 percent of the adult population aged between 15 and 49 in 2001 (UNAIDS, 2002). The population in this age-group was estimated at 1,007,535 or 48 percent of the total population (Ministry of Health and Social Welfare, 2000). Today, it is estimated that more than 270 000 Basotho are living with HIV and AIDS and the economically active age groups are highly affected. Surveillance efforts were intensified through sentinel surveys among pregnant women who attended antenatal clinics; the first survey conducted in 1991 and the latest was conducted in six sentinel sites in 2003. The sentinel HIV/syphilis survey of 2003 indicated that HIV prevalence continued to increase amongst pregnant women in Lesotho and that the information could be used for estimating the prevalence in the general adult population (Ministry of Health, 2003).

The responses to the epidemic in Lesotho evolved from mainly prevention in the early 1990s to care and support of people living with HIV and AIDS (PLWHA). The National HIV and AIDS Policy and the National AIDS Strategic Plan for 2002/2005 period was developed with broad strategic objectives but during the plan period, emphasis has been on prevention, care and mitigation of AIDS impacts. The Government of Lesotho with the assistance of local non-governmental organizations (NGOs) and the international donor community developed various structures and processes in response to the epidemic which was spreading fast. In 2000 the Lesotho AIDS Programme Coordinating Authority (LAPCA) was established to guide and coordinate the national multi-sectoral response. In addition a National AIDS Committee (NAC) comprising cabinet ministers was established to advise, guide and endorse the HIV and AIDS programmes while also soliciting commitment and support from structures outside government. A multi-sectoral task force was established consisting of units and individuals known as HIV and AIDS focal points in government, UN and bilateral departments/agencies, NGOs and the business sector. In an attempt to decentralise and promote ownership of the HIV and AIDS interventions, District AIDS Task Forces were set up comprising government structures, community based organizations (CBOs) especially community home-based care and support groups as well as NGOs at district level.

HIV and AIDS prevention and mitigation was consolidated through strategies which had limited focus and benefits. They included a commitment of 2 percent of each government ministry's budget to HIV activities for which the direct beneficiaries were civil servants. Another programme was the prevention-of-mother-to-child-transmission (PMTCT) in public hospitals which introduced *Nevirapine* drugs in 2002. Voluntary counselling and testing (VCT) was also promoted because of its significance as an entry point for care and prevention services. However, due to lack of visible benefits to those who tested HIV positive, especially unavailability of ARVs, VCT was not popular; hence many people would know about their HIV status when they consulted hospitals due to illness or antenatal care in the case of pregnant women. The 2002 Lesotho Reproductive Health Survey established that since VCT was not a common practice, personal knowledge about individuals who had HIV and AIDS or died from the disease reported in the survey, 34 percent and 17 percent of the urban and rural respondents, respectively, was based on suspicion, rumour and unproven allegations in the communities (Bureau of Statistics & UNFPA, 2003). The problem of the increasing number of orphans who lost both parents within a short period of time is usually one of the indicators of the prevalence of HIV and AIDS in the communities.

Apart from poor HIV testing in the pre-ARV era, knowing about others' HIV and AIDS status was made difficult by the common tendency to maintain confidentiality. Informal caregivers, including family members are advised to follow the universal principles of precaution by protecting themselves when they provide care to sick family members. Secrecy concerning HIV sero-positive status has been directly encouraged by the policy of confidentiality adopted internationally by organisations in the lead of the fight against HIV and AIDS and the human rights fraternity. The policy has been followed by the health care institutions in different cultural contexts including African societies even though there is a long-standing controversy concerning its appropriateness in cultures where illness may not be dealt with in an individualistic manner. For example, there are inherent contradictions in confidentiality and home-based care as will be illustrated by the experiences of the caregivers who were used to the details of diagnosis being shared among the family members. Culturally, the uninhibited sharing of information about the causes of illness was usually demonstrated by a norm practised during funerals whereby a family representative provided a public narration of the circumstances which led to the death of the deceased to the mourners who listened attentively. While this practice still persists, the narrator is mostly likely to focus on the symptoms but will not reveal the medical diagnosis, leaving much to speculation. But also common in the era of AIDS are comments by mourners after viewing a corpse that it did not resemble the diseased. The extreme effects of the disease on the body have been associated with lack of effective medication that may curb the virus.

Definitely, confidentiality was adopted to protect the infected people from stigmatisation and discrimination which were believed to constrain the control of the spread of HIV infections among populations by producing silence. Some of people who were infected or associated with infected individuals faced stigma within their families, communities and other spheres of life such as schools and work. Although health care institutions were supposed to promote attitudes and practices which supported the PLWHA, the reluctance among the general population to consult hospitals for HIV testing might suggest that these institutions might not be perceived differently. Parker and Aggleton (2003) recommended that research should establish how policy and institutional practices may foster AIDS stigmatisation. Poor support and lack of compassion of health care workers towards PLWHA had always been doubted but their behaviour was mainly explained in terms of burn-out and feeling burdened. These were some of the considerations when home-based care for PLWHA was adopted. But how the family caregivers may experience such ambiguity around a perturbing illness needs to be explicated.

Although antiretroviral therapies (ARVs) are referred to as a 'life jacket' in the absence of vaccines and curative medicines, they are also notorious for their high cost and for most of the period of the HIV and AIDS epidemic, their availability globally was influenced by the profit-making interest of the multinational pharmaceutical corporations of the West. Lesotho, as with most southern African countries affected by the high infection rates, adopted the no-ARV approach on account of scarce financial and human resources for almost two decades of the epidemic. Generally, the medical treatment approach followed in the public health sector for the PLWHA has been "a minimum package of care" meant to treat the opportunistic infections (Government of Lesotho, 2002b). For most of the period of the epidemic treatment was provided for some of the common opportunistic infections. Especially, oesophageal candidiasis and cryptococcal meningitis were treated free through the Lesotho-Pfizer Partnership (Government of Lesotho, 2002b), also sexually transmitted infections (STIs) and tuberculosis (TB), all closely associated with HIV and AIDS infection in recent years (Ministry of Health and Social Welfare, 2000). For example, from the early 1990s it was noticed that there was a significant increase in TB cases due to HIV infections while effective TB treatment was undermined by co-infection with HIV thus leading to multi-drug resistant (MDR) TB. Treatment provided in the public health sector did not include ARVs and in most situations clinical testing for HIV was not done. The co-existence of certain symptoms was used as proxies for HIV and AIDS diagnosis in most public health facilities while some private facilities depended on South African institutions for clinical tests, thus making HIV testing unaffordable to most people.

Recently, antiretroviral (ARVs) treatment became part of the policy agenda when the government requested funds from the Global Fund in 2002 to control AIDS and provide continuity of care by introducing ARVs as well as strengthening tuberculosis treatment. The first health care centre for PLWHA known as the *Sankatana* AIDS Clinic was opened to provide antiretroviral therapies in the public health sector in 2004. Earlier at the beginning of the year, the state through the King and the Prime Minister was reported to have had noted the concern on the rise of HIV/AIDS scourge in the country with the King identifying unavailability of ARVs due to their high cost as one of the factors that complicated the situation in Lesotho (Sithetho, January 2004). Today, most of the hospitals provide VCT, PMTCT and ARVs in AIDS specialised clinics.

Prior to 2004, some private practitioners and only one CHAL hospital – Maluti Hospital in the Berea district prescribed the ARVs. The hospital launched an ambitious comprehensive care and treatment programme which included food security and income generation components for households affected by HIV and AIDS within its health service area in 2001. Provision of ARVs at Maluti was part of a global initiative with the key pharmaceutical company that manufactures ARVs – the Bristol Myres Squibb company – which formed partnerships with agencies in the developing countries to make the drugs needed for the treatment of HIV and AIDS available through its programme of "*Secure the Future*". In theory, the availability of ARVs meant that about 250 000 people found within the Maluti HSA could access the treatment. However, the hospital practised stringent measures and provided the drugs on the basis of the patients' ability to pay for the laboratory tests, monitoring and ARVs (Government of Lesotho, 2002b). The government partnered with the same company four years later.

Lack of access to antiretroviral treatment whereby since the 1990s only two hospitals – Queen Elizabeth II and Maluti hospitals – provided post-exposure treatment for health care workers (SAfAIDS, 2003) while the latter also provided ARV treatment for individuals who could afford the treatment – compounded the illness situation in the country in terms of high incidence and severity of symptoms. Furthermore, there has been a growing demand for health care services due to increased AIDS-related illness in the country which led to an increase in bed occupancy with most hospitals unable to cope with the demand (Government of Lesotho, 2002). Kimaryo, Okpaku, Githuku-Shongwe and Feeney (2003: 69) further note that due to "the lack of basic medicine and qualified personnel, health facilities are struggling to cope with the provision of appropriate treatment and care".

The question of how care for the ill members of society was organised is pertinent because the HIV and AIDS prevalence situation and the inadequacies of the forms of medical treatment depicted above suggest that Basotho have been inundated by the problem of extensive AIDS-related illness. The situation necessitated rigorous care and medical treatment responses with financial implications for the health care institutions and affected families. It would appear that health care for PLWHA was initially provided following the traditional health care provision system consisting mainly of the public hospitals and those owned by the Christian Health Association of Lesotho (CHAL) with minimum adjustments made to the internal structures and processes of the system in response to the dynamics of the epidemic. For instance, the hospitalisation of the patients who were severely ill continued to be practised with robust nutritional interventions – boosters – and medical treatment of some of the opportunistic infections leading to some patients recovering and being discharged to home. Most would be readmitted several times during their illness career.

Since the beginning of this decade, the government began to take into account the increased burden on health care services, especially hospital services, as a result of the epidemic. There was increased morbidity among what Barnett and Whiteside (2002: 308) describe as "people who are not normally users of health care: young adults". The increase of the burden of caring for people with HIV and AIDS and an increasing number of hospital beds occupied by patients with HIV-related illnesses amidst inadequate staffing in health care institutions were a concern (Ministry of Health and Social Welfare & WHO, 2002).

Reliance on the minimum treatment strategy continued despite the volatile nature of the HIV infection and although one of the prominent messages was the possibility for HIV positive people to pursue quality life despite the infection, the reality for most people was quick progression into the AIDS stage and frequent illness episodes which eventually led to premature death. Due to prolonged illness, the idea that HIV and AIDS were chronic conditions and their symptoms manageable remained elusive in the absence of ARVs. As in most resource poor countries, the majority of the members of society infected with HIV could not lead rewarding lives as could their counterparts in the developed societies following the availability of ARVs and the highly active antiretroviral treatments (HAART). Consequently, the health care system managed the flux of patients in overstretched hospital facilities by encouraging the help-seekers to consult primary level services while hospitalisation admissions and stays were significantly reduced.

These practices led to increase in the incidence of households caring for chronically ill family members. A national survey on core welfare indicators reported that 6.9 percent and 5.1 percent of the rural and urban households, respectively cared for the chronically sick who could not perform their usual roles for three months or more in the twelve months prior to the survey (Bureau of Statistics, 2003). Berea district, which was the site of the current study, reported the highest incidence with about 10 percent of the households reporting care for chronically ill family members. It was also interesting that it was mostly the poor households that provided care. The study also indicated that 7.2 percent and about 6 percent of female headed and male headed households provided care but did not report the gender of the caregivers. Despite the co-existence of CHAL and government health institutions in some of the districts, most of the households identified the latter followed by family or neighbours and traditional healers as the sources of help in caregiving. Less than 10 percent approached private services. The study did not reflect the assistance provided by myriad non-governmental agencies present in the districts.

The principle of continuity of care implied that the link between the home and the hospitals would be maintained to ensure that the patients did not have their care disrupted. This is because ideally, home based care is not supposed to lead to the neglect of those who need care and medical treatment for the treatment of opportunistic infections and palliative care is integral to provision of care with a human face. Continuity of care assumed that it would be possible to consult hospitals, secure hospitalization when it was necessary, and that families would afford the long-term treatments available for the various opportunistic infections.

Although Lesotho has historically been characterised as a poor country, extreme poverty among most households was averted by remittances from the male dominated migrant labour in South African mines. Remittances from labour migrants have been an important source of household incomes for more than a century. As a result the welfare system was underdeveloped while only an insignificant proportion of the citizens depended on government for their well being. However, due to the declined economic opportunities and retrenchments in the sector since the 1990s many households in Lesotho have been deprived of regular income and the ability to afford basic needs such as health care services has declined. It has also been argued that inter-household coping mechanisms in some rural areas have weakened due to extreme poverty thus reducing the resilience of households (Turner, 2003) including their capacity to cope with stressors such as chronic illness of breadwinners. Many households depend on irregular income generation activities which may be negatively affected by responsibilities such as long-term caregiving and the disruptions likely to occur when a family member has a protracted illness. Low and irregular incomes imply that most households would find it costly to travel to the hospitals each time an illness episode was experienced.

Regrettably, today economic migrant labour is identified as a significant contributing factor to the high HIV infections (Government of Lesotho, 2002a; SAfAIDS, 2003) and a threat to livelihoods. Historical evidence suggests that the association between migration and disease is old: a significant number of men were retrenched from the South African mining industry because of TB and other respiratory infections (Tsikoane, 1998; Makoae, 1998). However, since TB was highly curable prior to the advent of HIV and AIDS, some would be re-employed upon recovery. This has changed because most men who are retrenched on poor health grounds do not recover to resume their economic responsibilities. In many cases co-infection with TB and HIV and AIDS is the cause of illness. Within the family context, the common trend involved men who would not be informed about their HIV status when they were discharged by their employers or would not disclose their status to their spouses who unknowingly became infected by the virus. Anecdotal evidence also suggests that many women who migrate to work in other economic sectors in South Africa (SA) usually return home severely ill from incurable illnesses. This situation has led to the perception that certain host areas in South Africa are a health risk with AIDS metaphors such as 'Bekkersdal' used to describe the cross-border migration of women and its health-related consequences. Both internal and external migration by male and female labour is linked to HIV transmission (Kimaryo et al, 2003).

Another reason for migration among women is marriage. Customarily, women relocate from their parents' home to reside with their husbands' kin. The Lesotho demographic survey established that life-time migration among the ever-married women was higher than for persons who had never been married (Bureau of Statistics, 2003). The cultural expectation would be that the matrimonial kin have the obligation to provide care for women married to their families. Traditionally, this was expressed when newly married women were sent-off; they would be cautioned about their newly acquired status and place of belonging: *"E-ea ngoan'a ka! Ngoan'a moroetsana o shoela lichabeng, a lahloe ka lelahlo la moo a nyetsoeng teng"* [Literally translated: *Go my child! A girl child dies among strangers, and is buried according to the customs of those she is married to*]. Abandonment and rejection by family members have been identified as some of the problems which PLWHA may encounter as their health deteriorates (Government of Lesotho, 2002).

This description provides a backdrop against which the experiences of the family caregivers who provided home-based care for people who were diagnosed with HIV/AIDS in Lesotho in the pre-ARV era may be understood. HIV/AIDS and its impact on the formal health care system were partially responsible for the declined capacity of the health facilities to cope with the increasing care needs. Therefore, HIV/AIDS was the impetus of home-based care and the people with AIDS-related infections are the main recipients of home-based care. The various elements of the care environment influenced access to medical care and continuity of care within the home sphere and influenced the experiences of the caregivers, but so did the behaviour of the care-recipients.

Introduction

This study sought to explore the experiences of the family caregivers who provided care for chronically ill patients who were in home-based care and were diagnosed with HIV/AIDS in Lesotho before the government introduced public financed ARVs. It adopted the caregivercentred perspective and used it as a lens through which to see the world of care. This study builds on the work of the theorists of care – Noddings (1984) and Tronto (1993) – as well as other scholars who have analysed care work and have contributed useful conceptual tools and theoretical understanding for this commonplace human activity. Caregiving is a process which entails relationships which are embedded in emotions and activities which individuals carry out to maintain life, dignity and ameliorate suffering. The study attempted to contribute understanding on what experiences the caregivers had and how they occurred. It will be argued that for the studied caregivers, caregiving was largely chaotic and stressful but there were also encouraging moments for others. Irrespective of their nature, their caregiving experiences cannot be understood in a vacuum.

The various elements of the care environment namely; confidentiality about diagnosis which excluded the caregivers, a "minimum package of care" meant to treat some but not all the opportunistic infections, high cost of antiretroviral drugs and restrictions on hospitalisation of chronically ill patients produced chaotic illness and care situations which led to the family caregivers having mainly stressful experiences in their caregiving role. These experiences related to the initiation of caregiving which was complicated by delay and the intricacies of obtaining medical diagnosis, the caregivers' encounters with the care-recipients' corporeality, their perceptions about appropriateness and in/efficacy of the prescribed medication, the attitudes and behaviour of the care-recipients in relation to medication, food and bathing as devices that the caregivers used to ameliorate the symptoms and their consequences and access of the care-recipients to medical care in the form of drugs and hospitalisation.

Some of these elements defied the most fundamental assumptions about care identified by the scholars of care: relationality, interdependence and responsiveness. They also disregarded the canons of the *ubuntu* philosophy on which the expectation that the ill in society would receive support from the family and community members were based. These elements were the policy issues which included confidentiality regarding the HIV/AIDS diagnosis of the individuals who were in home-based care, the policy of government which entailed public financing of a minimum package of care which excluded providing ARVs to PLWHA but emphasized the non-medical responses to the epidemic couched in the discourse of "unavailability of medicines for HIV/AIDS", rationing which entailed selective financing of treatment of the opportunistic infections affecting PLWHA; the medical factors included maintaining the conservative doctor-patient relationship which excluded the family caregivers in matters concerning diagnosis and prognosis of AIDS-related illness, the doctors' prescribing practices which were influenced by unavailability of ARVs and the concern with treatment costs, the responsiveness of the health care services to the care needs of the patients as perceived by the caregivers, for example, decisions concerning the hospitalization of the patients which did not take into account the perspectives of most of the caregivers despite their proximity to the illness situation; efficacy of treatments and the social and economic factors: AIDS stigma, poverty at household level which constrained the caregivers' options in care and determined the patients' access to medical treatment as the illness progressed, the contribution of the care-recipients to the care relationship and how they communicated the illness including their receptiveness and responsiveness to care.

The outcomes of this care environment included lack of openness in most caregiving relationships which contributed to delayed initiation of caregiving, ambiguity regarding the medical explanation of the distressing symptoms and suspicion that the illness was due to HIV/AIDS. Generally, the caregivers tended to be passive in these relationships with care being a one-way flow of inputs by the caregivers. The possibility that the cared-for could also resist care had important implications for the caregivers' experiences. These factors influenced how the caregivers experienced the initiation of caregiving, the search for diagnosis and access to medical treatment, the prescribed treatment and its outcomes especially as perceived through the ferocity of symptoms and the patients' corporeality.

Therefore, the predominant elements of the caregiving experiences were emotional response and work, delayed caregiving, chaos and stress, physical tasks, the care-recipient's behaviour, difficulties in obtaining diagnosis, secrecy, suspicion, doubt, medicines, life-threatening symptoms, the body of the patient, access to medical drugs and hospitalisation of the patients.

Chapter Two reviews the literature on care in society across time and cultures and evaluates some of the factors which have led to shifts in the locus of care in societies with some periods dominated by institutionalized care and others by informal care in the communities. It examines the feminist scholarship on care and in particular draws attention to the contribution of the moral theorists of care who emphasise that unlike the male oriented justice perspective which is based on universal principles of autonomy, independence, rules and rights the *ethic of care* is sensitive to local contexts and embraces emotions as part of social relationships while also acknowledging interdependence and relatedness in caring relationships. The *ethic of care* complements the African philosophy of *ubuntu* in its recognition that principles of the traditional western ethics which encourage individualistic values such as autonomy may not be consistent with the fundamental reality about human beings especially in situations where care is inevitable. Attention is also paid to the different emphases made by writers who conceptualise care from other standpoints such as disability. The value of this strand is its criticism of a passive care-recipient.

In addition, the literature on family caregiving is examined to illustrate that in the context of chronic illness, the dominant view is that caregiving is burdensome. But there are writers who point out that caregiving is not inherently negative and suggest that where the larger culture supports care by the family, caregiving may be a fulfilling experience. This view opens up the analytical opportunity to explore care contexts and try to understand how the features of the care environment may uniquely influence the experiences of those who provide care within informal relationships. Accordingly, the literature on how a phenomenon described as the caregiver burden arises in caregiving provides a useful starting point for analysing home-based care for patients with AIDS-related illness. A powerful conceptualisation of the difficulties encountered in caregiving is the notion of stress proliferation which recognises that the context of care contributes to caregivers' experiences. Taking this into account, the theoretical debates concerning the various aspects of the care environment in Lesotho namely, availability of ARVs, stigmatisation of HIV and AIDS, confidentiality and the implications of poverty on caregiving, are reviewed to provide relevant context for the caregivers' experiences.

Chapter Three discusses the procedures and techniques that were used to obtain the evidence needed to address the following broad research question: what were the experiences of the family caregivers who provided home-based care in Lesotho in the pre-ARVs period? A qualitative social research methodology was adopted because the research goal was to understand the experiences about caregiving from the participants' perspective.

The study was meant to document what they experienced and how they experienced it. It adopted phenomenology as a philosophical and theoretical approach to understanding the experience that people had about caregiving as part of their 'life world'. The chapter also explains how the caregiving experiences of the twenty one (21) caregivers were studied using the phenomenological approach – collection of their descriptions, capturing and analysis of the data. It provides a description of the characteristics of the study participants.

Some of the key experiences of the caregivers with the process of initiating care at home were the delay in assuming the responsibility and the intricacies of obtaining medical diagnosis for the illness which most caregivers found upsetting. Chapter Four discusses the various factors which led to the caregivers experiencing the assumption of the role poignantly. The tendency of some individuals to deny that the physical changes which the family members observed about them required medical attention, preoccupation of the caregivers with on-going caregiving within the family, poor communication between the hospitals and the families concerning the impending illness, and falling ill while away from home due to the economic and social commitments of adult life which are closely linked to migration influenced how soon caregiving could be initiated. The caregivers depended on others including the patients and members of kin who lived with the patients to communicate the illness before it was advanced. Their first encounters in situations where they did not normally live with the patients were distressing because they found patients with severe symptoms yet without adequate care. Despite the cultural expectation that the matrimonial kin have the responsibility to provide care for women married into their families, it seemed some of the women faced vulnerability due to inadequate care. Also, the social networks through which ordinarily provide access support and care may be weak for migrants who experience illness which introduces severe debilitation and high dependence on others. These dynamics suggested that informing potential caregivers about one's imminent illness or returning home when early signs of illness were experienced could save the caregivers from the distress they experienced at the early stage of caregiving.

Although family caregivers actively participated in the search for diagnosis, they rarely had definite information that the illness of their relatives was due to AIDS. They sought medical diagnosis in anticipation of knowing the underlying cause of the symptoms which were unusual and the disease which engendered intense emotional and physical suffering. They motivated the care-recipients to pursue diagnosis since sometimes they suspected HIV/AIDS but would not directly suggest with the family members. They also expected the doctors to use the diagnostic scientific technology and provide conclusive results which led to prescription of treatment. However, one of the distressing and unexpected outcomes was outcomes which implied uncertainty of the part of the doctors. The caregivers hardly associated medical knowledge with uncertainty, therefore such outcomes rendered diagnosis questionable and prescriptions could also be doubted. Especially when medical diagnosis did not match lay interpretation of the symptoms or it shifted from one outcome to another, diagnosis became a complex process and a contested area in caregiving and it was a stressor. They were also aware of the practice of confidentiality or what they referred to as the "doctor-patient secret" which they criticised for excluding the family members who provided care. Some of them resented the practice and felt exploited by the care-recipients and the hospitals alike. The caregivers who knew that the care-recipients were ill because of AIDS appreciated this and observed that their caregiving experiences improved thereafter because they could comprehend and contextualise the symptoms, while access to medical treatment and support from the hospitals also improved. They also ceased to search for diagnosis and focused on attaining maximising care.

The analysis of the experiences of the caregivers as they assisted the patients to be admitted into the hospitals provides part of the answer to how they came to provide care at home. Chapter Five discusses the experiences of the caregiver in terms of the circumstances under which they sought the care-recipients' hospitalisation, the outcomes of these actions and their consequences in caregiving. In a few cases the health care workers provided guidance to the caregivers about how care would evolve and were not formally informed about the change of practice concerning care for the chronically ill. But mostly the caregivers used their discretion and sought hospitalisation when they perceived the symptoms life threatening. For example, difficult breathing due to incessant chest pains and inability to eat or swallow medication made the caregivers consider hospitalisation.

Some of the caregivers who would have expected the patients to be admitted felt disillusioned when the patients were not admitted, sometimes they returned home without conclusive clinical assessment and with or without medication. Failure to secure admission was devastating because the caregivers considered it when they felt incompetent to deal with the illness at home but also because it introduced feelings of despair on the part of the patients with negative consequences for sustaining hope in caregiving. It also introduced feelings of being discriminated against since the patients were sometimes excluded due to their symptoms. Access to hospitalisation could improve with time as the caregivers developed rapport with some of the hospital personnel but in particular, the caregivers who knew the HIV and AIDS status of their relatives had guaranteed admission for them because they had the understanding that care for AIDS patients was not their sole responsibility; they expected the hospitals to take over whenever they felt incompetent to handle the situation. The fact that knowing the HIV and AIDS diagnosis influenced access to hospitalisation meant that the majority of the caregivers could not secure this component of continuity of care for the care-recipients because they did not know this about the person they cared for.

Irrespective of the justification for the unavailability of ARVs in the public health care system, the litmus test for the quality of medical treatment which the PLWHA obtained was whether, from the caregivers' perspective, it helped the patients to lead a symptom free life and reduce the burden of care within the home sphere. It was difficult for the patients to maintain symptoms-free existences as a result they experienced frequent illness episodes and the caregivers spent most of the time seeking medical help. Medical care for patients was mainly influenced by diagnosis. The caregivers of the patients who were known to be TB or HIV and AIDS positive had support in the form of access to the free medical treatment packages. Others did not qualify for subsidised health care despite having what could be opportunistic infections due to declined immune systems. Therefore, 'operational diagnosis' as understood by the caregivers influenced access and the form of treatment. The argument that medical treatment which does not include ARVs is inadequate has been raised from both within and outside the medical spheres in sub-Saharan Africa.

Chapter Six examines the caregivers' experiences about medication and it takes as the point of departure the fact that they perceived medicines as integral to home-based caregiving and that the actions of the doctors in this regard were perceived with a high degree of sensitivity. The experiences included anomalous prescribing practices in which the doctors provided medicines which did not match the caregivers' perspectives of what should be appropriate treatment. Consideration of the cost of medicines which was done to the detriment of care disturbed the caregivers and sometimes they doubted the integrity and intentions of the doctors.

The perception that chronic illnesses fall within the realm of knowledge which is of less interest to the medical profession because it is unusual for doctors to play the traditional role of curers cannot be ignored. Especially as the disease progresses, chronic illnesses do not fulfil the assumptions of science such as control and prediction. This attitude combined with the ideas of demedicalisation of HIV and AIDS care – or de-emphasising of the significance of medical drugs while accentuating the role of lay people in managing AIDS-related illness – and resource rationing to produce poignant caregiving experiences of the caregivers. Their experiences about access to the different forms of medical treatment and their efficacy could be understood in the context of the minimum package of care which did not include ARVs and was meant to be freely available for treatment of certain opportunistic infections and not others. They also reflected the strong beliefs they had about the role of the doctors and medicine in supporting caregiving. Some of the poignant experiences of the caregivers were in relation to providing care without medication or knowing that the medicines which were prescribed would not produce recovery. Due to poverty and debilitation it was difficult to access medical treatment available in hospitals using the relatively cheap means of public transport. Instead, privately arranged transport was preferred to overcome difficult mobility and ensure the dignity of the patients who could also have symptoms which the caregivers perceived as humiliating, especially diarrhoea. To sustain the argument that in care there is interdependence between the carer and the cared-for, the experiences of the former regarding the behaviour of the latter when medicine was concerned are analysed. Since the caregivers considered it necessary to maintain hope despite the severity of illness, they depended on the care-recipients for their own emotional wellbeing. Taking medication was not physically demanding but emotionally distressing because medicines were perceived as the main way in which health could be regained or the symptoms alleviated.

Chapter Seven analyses caregiving experiences about the body and bodily care. The inability of society to make appropriate medical treatment available for the PLWHA led to the bodies of the patients undergoing severe strain as the system was attacked by the highly volatile virus which has the capacity to affect almost all the systems of the body and change its physical appearance in profound ways. The ARVs would thwart the disease. The physical appearance of the body could be worsened by poor nutrition associated with HIV infection and the widespread food insecurity in the country at the time. Most care-recipients depended on food parcels which were distributed by the state and non-governmental agencies which worked with the hospitals in the Berea district to support the patients in home-based care who were mainly AIDS patients.

The body was the focus of care and this entailed observing and perceiving the pain and suffering which the patients endured and taking responsibility to change the undesirable conditions of the patients. Managing the various symptoms especially those which manifested externally by ensuring that the bodies consumed food and medicines to maintain or gain vitality was important. By maintaining physical contact with the cared-for through touching and seeing their bodies, the caregivers could perceive the bodies as communicating hope and suffering simultaneously and these produced complex experiences.

The bodies were dynamic in that they were the media of care but could also create dilemmas for the caregivers because they consistently failed to respond to care, resisted it sometimes, or even pose risk to the caregivers, thus creating stress in caregiving. Arguably, they expected the cared-for to be receptive of and responsive to care. The behaviour of the care-recipients in relation to food, whether voluntary or involuntary, was negatively perceived if it contradicted care goals. Similarly, resistance to being bathed produced unbearable stress for the caregivers because they perceived bodily care as inherently linked to maintaining physical appearance and the dignity of the care-recipients. Feeding and bathing the bodies were both physically and emotionally demanding yet necessary for alleviating pain and sometimes the only ways in which the caregivers could show compassion, especially when medicines were not available. Resisting help with bathing could also be a strategy by the care-recipients to maintain secrecy about the effects of extremely disfiguring infection which affected the genitals, and which probable affected their self-esteem negatively. Gender differences between the caregiver and recipient could exacerbate such tensions. Under such circumstances care was threatened as the caregivers used a variety of strategies to instil compliance and ignored the emotional concerns in favour of the physical needs. They could also feel incompetent in the role. Finally, part of the stress emanated from the bodily substances which the caregivers perceived as risky or disgusting. Again, depending on what they knew about diagnosis and whether the information that the illness could be linked to

AIDS was endorsed by medical personnel, the caregivers hesitated to protect themselves from possible infection. They were worried but would not jeopardise family relations by adopting practices that would imply that they associated the illness with AIDS because the disease was taboo in their families.

Finally, the study has drawn a number of conclusions about the caregivers' experiences with home-based caregiving in Lesotho and how they occurred. On the basis of the narratives of the caregivers, it may be concluded that due to the care environment which prevailed and the individual economic situations of the caregiving households, caregiving was largely characterised by stress and painful experience. The predominant elements of the caregiving experiences which contributed to their experiences were disorder, confidentiality and ambiguous diagnosis which precipitated doubt and suspicion. The ineffective medicines and difficulties in obtaining hospitalisation when it was necessary constricted care and produced stress, especially because most caregivers did not have comprehensive information about diagnosis and how it would affect the care plan over time. These experiences highlight the significance of open communication between those who provide care and those who seek it. They also suggest that access to effective medicines which can control the life-threatening symptoms and improve the physical appearance and capacity of the body could be important catalysts in caregiving experiences.

CHAPTER TWO

LITERATURE REVIEW

This chapter reviews the literature on how societies deal with the needs of ill and dependent members through care. It examines the generic meaning of 'care' while also attempting to focus on care for the chronically ill in society. Care is one of the contested concepts in sociological and social policy literature. The concept has been employed quite extensively to understand one of the dilemmas that have become a prominent feature of the developed societies; namely, dealing with the responsibility of the general society and individual families to help their members with chronic illness and meet their needs with regard to health and activities of daily living. This concern was necessitated by pervasive chronic degenerative and mental illnesses among the aged who emerged in these countries as a distinct category in the 1970s. However, as a result of the HIV and AIDS epidemic, and other illnesses which are not curable and require long-term treatment, the problem is increasingly affecting younger age groups too. Although several assumptions are made when states decide on modalities for providing care, the experiences about providing care within the private domain differ according to the nature of disease and the context of care.

Illness as a social phenomenon

Illness is a subjective and social manifestation of the bodily discomfort and changes which people experience including the actions they take as members of specific social and cultural groups. Lupton (2003: 93) describes illness as "the social, lived experience of symptoms and suffering which is innately human. It includes recognizing that bodily processes are malfunctioning and taking steps to rectify the situation, such as seeking treatment". Gwyn (2002: 33) indicates that illness is learned behaviour which is expressed in terms of various frames available to the patient through their interaction with their family members, medical personnel and society as a whole. The notion of illness experience denotes subjectively ascribing meaning to symptoms or bodily discomfort. Unlike disease, illness is not a biological phenomenon; it is a life event with social meanings for the individuals whose bodies are afflicted with disease (Fife, 1994) as well as the people who are in social relationships with them. The sources of such meanings are diverse and sometimes incompatible; they include the dominant knowledge systems such as biomedicine, traditional knowledge and mass media (Brown, 1995; Gwyn, 2002; Lupton, 2003).

The experience includes the attempt by family members to understand illness by interpreting it from the symptoms while also sharing the burden emotionally and providing care (Toseland, Blanchard and McCallion, 1995; Thomas, Morris and Harman, 2002). The meanings inherently influence how people deal with the situation. For example, on the basis of their interpretations people seek different therapeutic measures. Especially in the African context, anthropological evidence indicates that when the illness is life-threatening, protracted and unresponsive to treatments, it may be linked to witchcraft or displeased ancestors, and the family would consult a traditional doctor or perform rituals (Hammond-Tooke, 1974; Sekese, 1991; Flint, 2001). Across cultures, illness does not only compel family members to engage in specific activities in relation to the patients' situation, they also '*share in* this experience' (Thomas, Morris and Harman: 2002: 530). Communication between the ill and family members is crucial in this process.

Social Responses to illness: The sick role, illness behaviour and care

In society, individuals' role performance may be affected by illness. Consequently, when individuals become ill it is in the interest of society to rectify the situation so that the typically disruptive nature of illness is minimised. In contemporary societies, this is particularly attainable if the disease is curable but even some incurable diseases may be managed medically to facilitate the functionality of the affected individuals and social units. In sociological literature, the involvement of others in personal illness is explicated through the *sick role* and *illness behaviour.*

Talcott Parsons developed the *sick role* theory in the 1950s to theorise about the expected behaviour of the ill in relation to the doctors. They should cooperate and comply with the doctors' instruction regarding treatment in order to escape being regarded as deviants (Lupton, 1994). In response to the patients' 'good' conduct, the doctors legitimise illness so that the sick are not accused of malingering: they are trusted as gatekeepers who rely on the medical ability to identify the objective cause of illness – disease. The doctor facilitates the achievement of the sick role and legitimizes the illness thus highlighting the role of medicine as an institution of social control (Hillier, 1986; Morgan, et al, 1985; Glenton, 2003). Consequently, the sick are exempted from the performance of normal social role obligations, not blamed for their illness, must be motivated to get well quickly, and use the doctor-patient relationship effectively by cooperating with experts (Turk and Kerns, 1985; Morgan, Calnan and Manning, 1985; Jary and Jary, 1991; Bury, 1997; Gwyn, 2002). Bury (1997: 85) argues: "In essence, the goal of the doctor-patient relationship is to try to ensure that the state of 'sickness' is temporary and to reintegrate the person back into their normal social roles as soon as possible". While such ideology enhanced the medical professional status, it may not be realistic in the light of the uncertainty which characterises clinical consultation but is usually unmentioned (Hatt, 1998).

Empirical evidence has increasingly criticised Parsons for emphasizing consensus between the sick individuals, (and their family members implicitly) and doctors. It also presupposes the supremacy of medical knowledge in diagnosing the cause of illness and identifying effective treatment which is a predominant feature of modernity. The *sick role* attracted criticism from various scholars for its emphasis on cure and limited application to chronic illnesses which became a prominent feature of most national health profiles in the developed societies in the 1970s. This optimism was understandable considering that the post-World War II period was marked by success in the ability of science and medical knowledge to control most diseases including reduction of infectious disease which had previously threatened human existence. Its main limitations are the assumptions concerning the duration of the role and efficacy of medicine (Lupton, 2003; Morgan, Calnan and Manning, 1985; Bury, 1997; Glenton, 2003) but this is a limitation which Parsons also later recognises in relation to chronic and terminal illness (Bury, 1997). When illness does not respond to medical treatment it becomes impossible to qualify for the *sick role*. In this situation the patients may have to adapt to their illness instead. Besides, when a patient is blamed for bringing illness on themselves by ignoring social norms, as is the case with HIV and AIDS, in the eyes of some people, the moral dimension of the illness becomes dominant (Lupton, 1994; Gwyn, 2004). Also, when the symptoms are conspicuous as they are with AIDS-related illness, malingering may not be suspected and the doctor's role as an arbitrator remains significant as they are expected to provide assurance by prescribing medicines since they are meaningful substances in clinical rituals (Van der Geest and Whyte, 1989; Gwyn, 2002).

Glenton's (2003) critique is interesting; she argues that even in chronic illnesses the *sick role* may still be relevant to a certain degree because it provides explanation for the expectations and behaviours that ensue in response to illness. In this way, Glenton's analysis makes a distinction between expectations, behaviours and outcomes. This observation is relevant in care situations where there is disparity in information among the parties involved. The expectations of caregivers who do not have complete information pertaining to diagnosis and prognosis may differ from others' who have less fragmented information. The experiences of the caregivers of the care-recipients who were ill because of HIV and AIDS should enhance understanding of how the sick role may be affected when confidentiality concerning diagnosis is a major aspect of the care milieu.

Illness behaviour describes the complex behaviour triggered by symptoms which a person may perceive as signalling illness. David Mechanic's work in the 1960s brought this behaviour to the attention of medical sociology. Mechanic defined illness behaviour as

> the manner in which persons monitor their bodies, define and interpret their symptoms, take remedial action and utilize various sources of help as well as the more formal health care system. It is also concerned with how people monitor and respond to symptoms and symptom change over the course of an illness and how this affects behaviour, remedial action taken and response to treatment (Skevington, 1995: 72).

It is how symptoms are perceived, appraised, and responded to by the sufferer (Morgan et al, 1985). It specifies the different paths that patients and their family members may take when they experience symptoms of illness. This behaviour may be influenced by such factors as the perceived significance of the symptoms, conflicting needs such as home versus work life and the accessibility and perceptions about the benefits of services (Bury, 1997). In the developing countries, accessibility of health services was improved through infrastructure development and decentralisation through primary health care.

The import of illness behaviour is that it describes an attribute which is patterned by socio-cultural and socio-psychological factors. These factors influence the sufferer's "predisposition to report … pain and illness" (Skevington, 1995: 72). This means that in any culture there are expectations about how ill individuals ought to behave when they experience pain or indications of organic disorder, and informing family members about one's illness in order to solicit help is one such expectation. It is as important as seeking medical attention and cooperating with experts who provide treatment. This is expected when a serious illness is diagnosed or when illness recurs. Communicating the illness is a catalyst in converting a personal experience into a social one. Depending on the level of discomfort and interference with the capacity to perform daily activities, members of society respond by providing care.

Defining care

Care is imbued with ideological and emotional debates by scholars who depict it in different ways because of their different theoretical orientations. Rudrappa (2004: 596) argues that the literature in the last two decades shows that "caring is a complex thing involving heart, head, and hands". For example, the moral philosophers in particular observe that giving and receiving care are fundamental to human existence (Tronto, 1993; Noddings, 1984; Bowden, 1997). They use the concept to analyse various human practices which are meant to meet different social needs. Tronto (1993) defines care as follows:

> On the more general level, we suggest that caring be viewed as a *species activity that includes everything that we do to maintain, continue, and repair our 'world' so that we can live in it as well as possible.* That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex life-sustaining web (Tronto, 1993: 103 – italics original).

This definition is valuable because it is all-encompassing and relevant in the analysis of caregiving by family members since in caregiving situations, the participants recognise that illness is undesirable. The concept explicates different aspects of social life but retains the connotations of providing or doing for others and an emotional response to others' predicament (Fry, 1992; Kuhse, 1997). Care primarily assumes social relationships that are based on affection, responsibility, commitment, service or paid labour (Peace, 1998: 59). For example, Bowden (1997) uses care to understand such mundane roles as mothering and friendship. The nature of the relationship is often linked to the place of care. It is also employed strategically to deal with such issues as the management of reproductive roles and work temporally and spatially (McKie, Gregory and Bowlby, 2002); domestic service (Graham, 1991) and the politics of disability (Lloyd, 2001; Morris, 1993; Hughes, McKie, Hopkins and Watson, 2005). The literature suggests at least three things: first, that care is inherent in human life, second, that it is not only a matter that preoccupies personal life but it involves mutual social action and has implications for collective resources, and third, that although both men and women are capable of practising care and both provide it, it is mainly women and the underprivileged social groups who provide care in societies (Akintola, 2006; Leclerc-Madlala, 2005).

What makes care intriguing is the fact that it is not possible for any person to depend entirely on themselves in situations that require it. Care entails the responses and interventions made when people have needs which they may not meet on their own. Such needs include nurturance, health, education and support for disability. Since these needs form part of daily existence, care is ubiquitous. Tronto (1993: 145) recognises this fundamental nature of care: "[C]are arises out of the fact that not all humans or other objects in the world are equally able, at all times, to take care of themselves". As various writers argue, illness and the related incapacity directly indicate that in varying ways, human existence is inherently based on dependency and vulnerability (Bowden, 1997; Sevenhuijsen, 2003; Tronto, 1993). Sevenhuijsen (2003: 185) observes that care is dynamic and that together with trust is integral to interpersonal relations thus bringing to the fore the recognition "that dealing with dependence and vulnerability on a daily basis plays an important part in human existence". It is therefore ironical that contemporary societies will emphasize autonomy and overlook the "contingency and vulnerability of human life" (Bowden, 1997:103) which people face from time to time.

However, certain social practices suggest that societies fail to openly acknowledge that dependency is intrinsic in care relationships. The biomedical perspective does not seem to incorporate the changing care needs of PLWHA across time and the dominant assumption about autonomy does not take into account the realities of bodily changes which inevitably undermine autonomous existence of individuals as the disease progresses. The study attempted to understand how the caregivers experienced some of the challenges which arose in home-based caregiving for chronically ill HIV and AIDS patients. The tensions that arise in these care situations should be understood from the caregivers' perspectives. For instance, when confidentiality as a principle of biomedicine transcends the medical sphere and influences informal relationships of care in the private sphere, it becomes obvious that the care-recipients' autonomy is assumed to be paramount. This expectation is interesting because it is certainly the opposite of the unequal doctor-patient relationship in which the patient becomes passive under the medical gaze in anticipation of help. There is a substantial body of literature on care which points out that instances of caring defy the ideas about individual autonomy and independence (Tronto, 1993). Understandably, the notion of confidentiality in HIV and AIDS raises concerns in different cultural contexts. The argument is consistent with the research regarding the state of the body in illness; that it is fundamentally transformed while at the same time its presence to the owner may be amplified in consciousness (Lawton, 1998; Bowden, 1997; Kelly and Field, 1996; William, 1996; Seymour, 1998). Lawton (1998: 134) indicates how the disintegration of the body due to cancer contravenes ideas of modernity about the individualistic body with boundaries and accompanying constructions of the person as a stable and independent being.

At another level, the care concept is used to describe the main structures and the social or ideological choices regarding the provision of welfare to citizens. For example, it may be used to denote the nature of the division of labour among the various sectors of society in the public and private domains – the welfare state and its institutions, the family, community, professions and market (Litt, 2004; Daly and Lewis, 2000; Sevenhuijsen, 2003; Allott and Robb, 1998; Bowden, 1997) and recently the local and international non-governmental organisations (NGOs) as part of the civil society. Within this conceptualization, the term social care is used to describe "the activities and relations involved in meeting the physical and emotional requirements of dependent adults and children, and the normative, economic and social frameworks within which these are assigned and carried out" (Daly and Lewis, 2000: 285). In this way, care becomes a concern for macroeconomic planning and public policy, and is one of the major policy concerns for many governments (Sevenhuijsen, 2003; Daly and Lewis, 2000). Care has resources implications and this is evident in both the social arrangements in the developed and developing countries where public agencies attempt to balance access to care with efficient management of public resources, albeit several inadequacies.

The philosophy of ubuntu and the ethic of care

Some African scholars believe that the African cultural context has not been genuinely incorporated in the responses to HIV and AIDS epidemic (Ankrah, 1993; Ramose, 2002).

Perhaps one may argue that this is a convincing observation with regard to confidentiality because it contravenes some of the core African philosophical orientations to life expressed in the *ubuntu* ethic. *Ubuntu* espouses the notion of caring which is inherent in most human relationships. It is reasonable that home care which is based on filial obligations is also implicitly or explicitly embedded in the *ubuntu* philosophy as recognized by such writers as Ramose (2002), Mbiti (1990) and Okolo (2002). Ramose (2002: 643) states that "*ubuntu* is the central concept of social and political organisation in African philosophy…It consists of the principles of sharing and caring for one another". Clearly, these social practices assume that mutual recognition and responsiveness should persist even where reciprocity may not be sustained due to severe illness, thus the care-recipient may not be absolved from the ability to contribute to the care process. But as Piliavin and Charng (1990:30) indicate the motivational features of altruistic behaviour is that it "must benefit another person, must be performed voluntarily, must be performed intentionally, the benefit must be the goal by itself, and must be performed without expecting any external reward". Empathy is also a vital ingredient in caregiving

The *ubuntu* views a person in the African context less in atomic existence than in social relatedness. The self is "essentially social, person-in-relation-to-others" (Okolo, 2002: 213); the "others" include the living, the dead and even the yet-to-be-born. However, Okolo further contends that the social is only the dominant category in understanding the self but does not imply that the individual is entirely deprived of his or her liberty and freedom. The difference is that such liberties are entirely exercised in interdependent and reciprocal relationships based on mutual respect. Ramose (2002: 329) argues that within the family context, the *ubuntu* principles remain vital in producing

> mutual recognition and respect complemented by mutual care and sharing in the construction of human relations. According to this understanding of the family, it is unethical to withhold or to deny *botho/ubuntu* towards a member of the family, in the first place and, the community at large.

It is *ubuntu* to provide care for relatives who are constrained by illness to meet their needs, but it is un-*ubuntu* to be unreceptive or indifferent to care. These views correspond with the ideas espoused by the proponents of the *ethic of care* because both subscribe to relationships based on trust. Generally, the 1990s ushered in a new way of thinking about care in the western thought. It transcended the earlier notion of burden to women and introduced broader conceptualisations of care based on the *'ethic of care'* (Tronto, 1993; Kuhse, 1997; Fry, 1992; Bowden, 1997) and as was articulated earlier by Noddings (1984). Tronto's (1993) discussion of the ethic of care is a critique of the feminist views about care and the negative attitude of the powerful groups towards care despite its central role in human life.

The work of philosophical feminists who approached care using moral theories became the benchmark for empirical studies on the issue of women and care in society. Taking the work of Carol Gilligan in the book titled *In a Different Voice* (1982) as their starting point these scholars juxtapose care with justice. They embrace what Kuhse (1997) identifies as a current development which basically challenges the traditional western ethics. Kuhse (1997: 116) quotes Martha Nussbaum (1995) who summarised this trend as follows:

> Anglo-American moral philosophy is turning from an ethics based on enlightenment ideals of universality to an ethics based on tradition and particularity; from an ethics based on principles to an ethics based of virtue; from an ethics dedicated to the elaboration of systematic theoretical justification to an ethics suspicious of theory and respectful of local wisdom; from an ethics based on the isolated individual to an ethics based on affiliation and care; from an ahistorical detached ethics to an ethics rooted in concreteness and history.

Noddings (1984) rejects the 'masculine' approach to *justice* based on reason, abstraction, universalism, rules and rights and proposes a 'feminine' *caring* approach which has its origin in emotions. Similarly, Kuhse (1997) argues that the justice tradition with its emphasis on impartiality and universal principles is flawed. She delineates the common themes in the care approach as sensitivity to context, relationships and responsibility to particular others. However, she cautions that the care approach does not necessarily reject the notion of principles entirely but the content of the traditional western thought as articulated above. This body of literature emphasises the relational and moral dimensions of care and conceptualises care as multidimensional. Noddings (1984: 48) argues that the caregiver and the cared-for are interrelated and each depends on the other in caring associations.

Accordingly, the cared-for have the obligation to reciprocate through responsiveness to care (Noddings, 1984; Sevenhuijsen, 2003; Tronto, 1993) and by being open to the one-caring. It is interesting that Noddings recognises that while this situation is what the carer prefers, he or she may not demand it from the care-recipient. But the attitude of the cared-for contributes to the care relationship and may be blamed for the moral depreciation of the one-caring. Sevenhuijsen (2003: 184) emphasises that "everyone is in principle capable of giving care". This assertion makes sense when we consider trust, responsibility, relatedness and interdependence as the core values of care. Most importantly, this understanding directs people in care relationships to be responsible for one another and to interpret their autonomy within relationships. Sevenhuijsen emphasises the interconnections between caring for the self, caring for others and caring for the world as key to human society and suggests that public policies could support these tendencies by taking the moral competencies of people seriously. The underlying assumption is that care is not a one-way relationship and that as a process it must be integrated. But the literature suggests that there is a possibility that the patients' demands may exceed the carers' abilities.

Tronto (ibid) conceptualizes care as both a process and a practice. There are seven important aspects of care identifiable from her concept of care. First, care is not inherently a gendered role in that both men and women are capable of caring, second, although care is fundamental to human existence it is rendered a peripheral position in society by associating it with 'otherness' and private life of the family thus relegating it to an inferior position and the realm of emotions – not rationality, that is, in contrast to economy or health, third, "care helps to rethink humans as interdependent beings" (ibid, p. 21), fourth, care may not be limited to dyadic relationships, fifth, caring activities are patterned by culture and differ across cultures, sixth, care requires resources, and finally, care implies the acceptance of some kind of burden and responsibility.

In addition, Tronto (1993) identifies four elements or phases of caring all of which are embedded in relationships and responsiveness in the process of care and argues that these phases are analytically distinct but related. Firstly, there is "caring about" which is the emotional dimension involving a strong feeling for someone and the recognition that there is a need for care. "It involves noting the existence of a need and making an assessment that this need should be met" (Tronto, 1993: 106) and it is based on a good understanding of the perspective of others. Through attentiveness the need for care is recognised and this requires one to "suspend one's goals, ambitions, plans of life, and concerns, in order to recognize and to be attentive to others" (ibid, p. 128).

Secondly, the dimension of "taking care of" assumes that identification of the need is translated into taking responsibility to meet the needs. It entails the actual actions that lead to addressing the recognised gap. Taking care of someone "involves notions of agency and responsibility in the caring process" (ibid, p. 106). This means that since caring is a two-way process both the carer and the cared-for have responsibility, and not necessarily the obligation to ensure that the care needs are met. Unlike obligations which politically emerge from the promises made, responsibility is a sociological concept "that is embedded in a set of implicit cultural practices, rather than in a set of formal rules or series of promises" (Tronto, ibid, 131-132). The family context is typical for producing a sense of responsibility to meet the needs of others for them and in illness the expectation is heightened, otherwise the family members may be blamed for neglect.

The third phase is "caregiving" which denotes the actual daily caring activities and tasks that directly attend to the care needs. "It involves physical work, and almost always requires that care-givers come in contact with the objects of care" (ibid, p.107). Rudrappa (2004: 596) too describes this particular component of care as "a more intense form of involvement encompassing knowledge and skill". Duffy (2005) identifies it as the nurturance framework of care that emphasizes emotions, responsibility, responsive action and relationship as its key elements. Competence is part of the moral quality of care (Noddings, 1984; Tronto, 1993). In caregiving, the needs for care must be met otherwise the care provided becomes inadequate. Therefore, resources are essential inputs in the provision of care such that in the absence of the necessary competence care is not viable. Recognizing that the ethic of care encompasses professional activities too, this element of the care ethic considers the primacy of the context within which ethical questions arise in professional decisions. Tronto (ibid, p. 134) states, "From a perspective of care, we would not permit individuals to escape from responsibility for their incompetence by claiming to adhere to a code of professional ethics".

Lastly, Tronto identifies *care-receiving* which recognizes that care happens within the context of a relationship between the caregiver and the care-recipient and assumes responsiveness to care on the part of the latter. It "recognizes that the object of care will respond to the care it receives" (ibid, p.107). The responsiveness of the care-recipient to care is also crucial in sustaining caregiving. This suggests that the recipient of care should not be indifferent to the care provided. This aspect recognizes the states of vulnerability and dependence inherent in care situations while also suggesting that there is a need to maintain a balance between the caregivers' and care-recipients' needs. It is equally important to note the distinction Tronto makes between responsiveness and reciprocity by suggesting that with the former differences and otherness are genuinely acknowledged.

The expanded and comprehensive frameworks of care suggested by Tronto (1993), Thomas (1993) and adopted also by Daly and Lewis (2000) are relevant for the current study because they provide the opportunity to analyse the family caregivers' experiences as shaped by the different aspects of the context of care including the carer-care-recipient relationship. These approaches delineate the various but interconnected components of care (Thomas, 1993; Lloyd, 2001; Sevenhuijsen, 2003; Rudrappa, 2004; Hughes et al, 2005; Thomas, Morris and Harman, 2002; Duffy, 2005). For example, Thomas (1993) deconstructs the care concepts and identifies seven analytical dimensions of care as: the social identity of the carer, the social identity of the care-recipient, the interpersonal relationships between the carer and the care-recipient, the nature of care, the social domain within which the caring relationship is located, the economic aspects of care and the institutional context in which care is provided.

They also allow the analysis to go beyond the practical care which carers execute daily and include other 'works' which they do to provide care. The physical activities that caregivers perform are certainly important and costly, but as Hughes et al (2005) point out, caring is not solely about performing mechanical tasks. Thomas et al (2002) observed that the 'companions' of cancer patients performed emotional work to maintain their own strength and that of the patients in addition to performing physical tasks. Likewise, the carers' experiences may not simply be explained in terms of the hardships without understanding the contexts that produce such experiences.

Conceptualising care as a process also helps towards understanding the caregiving experiences that evolve during the different phases of illness, the relationships and interaction between the caregiver, the patient and the professional healthcare. The advantage of this conceptualisation is that it emphasizes the agency of the parties involved in care including the cared-for. As a process, care may not be confined to a particular domain and the dynamics of attempting to meet the needs in care – both the caregiver's and the care-recipient's – across the spheres of care need to be understood. The understanding of care as relational, a responsibility with a mutual moral dimension opens up useful opportunities for studying caregivers' experiences. It is observed by some scholars that the bulk of the literature is on 'nurturance care', which exclusively addresses caregiving without paying attention to the other three dimensions of care – caring about, taking care of, and care-receiving - (Duffy, 2005). For example, the view that care is a process tends to be ignored thus leading to analyses that portray care as a fragmented activity that entails performance of tasks within specific spatial entities such as hospitals and homes yet the two spheres are interlinked and their connectivity should be seen as one of the prerequisites of sustained care.

Providing care for the ill

In contemporary societies, the biomedical health system is the main provider of health care services but there are also 'alternative' health services in different cultural settings. In Africa the traditional health sector coexists with the biomedical health care system (Green, 1994; Van Rensburg, Fourie and Pretorius, 1992; Muller and Steyn, 1999; Flint, 2001). But this characterisation is incomplete without the home sphere because irrespective of whether treatment is provided by a traditional or biomedical practitioner, the family members complement the 'experts' by providing residual care. Perhaps the construct of social care (Daly and Lewis, 2000) provides a comprehensive view on how the physical and emotional needs of dependent members of society are provided for through social relationships, policy and economic frameworks. It is useful to examine how societies organized health care across the various historical epochs and the context within which shifts between institutional and familial care occurred. Within these conventions of care, those who are confronted with illness in their families go through experiences which are influenced not only by the policies and structural aspects of care but also the medical discourses, that is, how reality about illness and disease are represented (Gwyn, 2002). HIV and AIDS caregiving experiences are framed by the aspects of the care environment.

Responses to illness through biomedical and hospital care

Consultation of medical care professionals when illness is experienced is a common feature of the help-seeking behaviour of individuals and families, especially when the symptoms are severe. Lupton (2003) indicates that modern medicine enjoys scientific status in contemporary societies and scientific techniques of observation are used to discover and label illness and this is the responsibility of the doctor. Various writers have also indicated how the development of scientific practices which 'objectively' lead to diagnosis of disease as a pathological condition within the body became prominent in medical practice in the nineteenth century; one of the achievements of hospital medicine (Armstrong, 1995; Brown, 1995; Lachmund, 1998; Lupton, 2003; Van der Geest and Finkler; 2004).

Generally, when lay people initiate the doctor-patient relationship, their expectation is that biomedical knowledge will identify the cause of the illness and provide treatment which is usually expected to lead to cure (Petersen and Waddell, 1998). In fact, the two are considered as the medical tasks that matter to doctors during clinical consultation (Gwyn, 2002). In the case of HIV and AIDS there are no curative therapies, and care outcomes of medical treatments which do not include antiretroviral drugs will certainly produce unique experiences for those who provide care. Karasz, Dyche, and Selwyn (2003) rightly recognise that in the context of chronic diseases and the HIV and AIDS epidemic in particular, the myth of a good doctor based on the technical knowledge of a doctor in curing pathological conditions which also valorised "his [*sic*] role in the treatment encounter [as] to prescribe treatment while the patient's role is limited to timely consultation and compliance with treatment" is profoundly challenged (Karasz et al, 2003: 1611).

The doctors constantly realise the ineffectiveness of their treatments and they are also aware of the stringent economic measures taken by planners to contain costs. Gross (1994) studied how implicit and explicit rationing impact on the medical decisions of radiologists in Britain and the US, respectively, and acknowledged that there was a drift towards the convergence of these two forms of rationing. But with regard to HIV and AIDS medical care there have been significant positive changes in the rich countries of the West including the US and Australia due to the introduction of AZT in the late 1980s and of the highly active antiretroviral therapy (HAART) in the 1990s in that doctors began to salvage the medical imagery in the management of AIDS-related illness (Carricaburu and Pierret, 1995; Persson, 2004). On the contrary, Liddell, Barrett and Bydawell (2005) observed that western medicine failed to provide African societies with a solution in the form of cure and reliable systems of controlling the epidemic while its hegemonic status ironically subverted the cultural responses to the disease. However, the literature is limited in terms of providing in-depth descriptions of the experiences of caregivers who operate within these paradoxes, especially with limited information.

The emotional distress that arises when a family member suffers from a life-threatening illness means that the patients and their families will find support of the physician indispensable as they try to cope with the disease. Gotay (1996) and Blanchard et al (1996) established this tendency in cancer care but it has also been reported with HIV and AIDS care (Nilmanat and Street, 2004). In the context where health care is organised on the basis of public hospitals, out-patient departments provide the bulk of routine services for the patients daily. But when the symptoms are life-threatening or expert knowledge is required to execute or review treatment, hospitalisation is usually considered relevant and the referral system normally allows patients to access this form of care. Bury (1997) and Lupton (2003) suggest that health care systems including hospitals can provide hope at a time of uncertainty while also providing information which was initially unknown concerning the prognosis of the illness. This is despite uncertainty being a persistent feature of the medical practice (Hatt, 1998).

Research literature on the hospitals in the developing countries suggests that non-medical factors influence the nature of services rendered to the poor who depend on public health care services (Andaleeb, 2001; Gilson, Alilio and Heggenhougen, 1994). Andersen (2004) provides an anthropological study of interaction between the patients and family members and the hospital workers in Ghana. Using the construct of "differential treatment" – she analyses how the doctors and nurses exercise their authority over patients from different social and economic backgrounds. Andersen argues that in every medical encounter the objective health needs, which were sometimes poorly assessed, were not as relevant as social status in determining how the patients were received. It would be impossible to envisage expert-patient relationships that are egalitarian or mutual in this milieu because the 'competence gap' enables the former to exercise control over the less knowledgeable patient

(Hillier, 1986; Morgan et al, 1985); especially in the developing countries, this would be exacerbated by differences in other social attributes such as gender, language and racial differences.

Presumably, when there are no barriers to institutional care, those who experience illness including the caregivers may consider hospitalization whenever they experience social and biophysical conditions which complicate caregiving (Lawton, 1998). For example, Thomas, Morris and Clark (2004) found that the cancer patients' and carers' preferences for place of death were influenced by the informal care resource, management of the body, experiences with services and existential views. They conclude that contrary to what many quantitative studies suggest, the choice of place of care or death was not resolute. For example, both carers and patients identified "contextual factors such as relationship with significant others, symptoms, physical limitations, interaction with health professionals and health services..." (Thomas et al, 2004: 2436). Williams (2002) makes observations regarding the assumptions about assurance of care at home and identifies some of the factors which promote home care instead of hospitalization as the availability of able and willing family carers and adequate caregiver support, but also suggest that the benefits may be realized when the patient is not too ill (see also Jackson, 2002), or home care services meet the needs at home. There is inadequate provision of comprehensive care for AIDS patients and home care as an alternative approach to care by the African states (Mupedziswa, 1998; Van Dyk, 2001). Levine (1991) questions public policies adopted in response to HIV and AIDS illness as they do not necessarily provide reasonable support for families.

The doctor-patient relationship and confidentiality

The medical perspective dominates in clinical encounters especially in the doctor-patient relationship which is a framework within which treatment is pursued. One of the principles which guide the relationship is confidentiality concerning the content of social interaction between the two parties. Robinson (1991: 280) describes confidentiality generally as 'protecting secrets' or 'non-disclosure of information'. Jackson (2001:4) observes that in medical practice it has always been a firm obligation owed by doctors to their patients as part of the Hippocratic tradition. It is about respect for the patient's privacy, right to autonomy and self-determination. Glannon (2005) indicates that within the doctor-patient relationship, confidentiality is an imperative. In particular, when a disease is serious or chronic this principle is crucial in establishing the patient's trust of the medical practitioners (Hawley, 1990). But it is equally safe to suggest that although considered the cornerstone of the trusting relationship between the doctor and patient, confidentiality has is usually taken for granted in the sense that it is certainly not expressed in routine health care interactions. Nevertheless, it remains an ethical obligation on the privileged doctor when in a care relationship with a vulnerable patient who divulges secrets in return for medical help (Robinson, 1991). But the dyadic doctor-patient relationship is a model of a care relationship and one which does not encompass the reality of these encounters, particularly when illness is severe and the sick person may not function independently. The understanding is that the care relationship is dynamic and transition to triadic relationships which involve informal caregivers is inevitable in chronic illness because deterioration in the capacity to be active is one of the few certainties in life. In other words, autonomy and confidentiality contradict care fundamentally.

Therefore, when health experts make a diagnosis and decide on the regimen to be followed to treat the illness, they are more likely to communicate this information to the family members who accompany the patients, even though they may pass it differently with some providing little information about how the illness might affect the caregivers (Taraborrelli, 1993). But, they generally communicate the outcomes of clinical investigations to family members. Even western trained medical doctors recognise that in African settings illness is a family concern and people who are defined as family usually know the 'cause' of illness because it is literally a family matter. Culturally, illness experience goes beyond being an individual problem; instead its causes and responses to it are socially interpreted (Flint, 2001; Jackson, 2002; Liddell, Barrett and Bydawell, 2005). However, this humanist understanding has drastically changed in the era of HIV and AIDS as confidentiality is emphasized and made a predominant aspect of care. This is despite the documented evidence that it is a hindrance in professional care and difficult to adhere to, hence compromises are made with patients' HIV status and medical records (Colledge and Maddison, 1992; Richards III, 1999). In the context of what Berg and Harterink (2004) refer to as the 'diluted' doctor-patient relationship, records remain integral to modern medicine but, their handling has been adapted to diverse specialities in medicine – they have ceased to be handled privately by the doctors. The need to prevent HIV infection at work is also considered even though universal precaution is a norm. Also, due to the earliest reactions to people living with HIV and AIDS by the public in some societies, the disease attracted the human rights perspective (Mann, Gostin, Gruskin, Brennan, Lazzarini and Fineberg, 1999) which resuscitated what had otherwise become a tacit principle in medical practice.

With the adoption of home-based care, confidentiality transcended the medical settings and permeated the home sphere and personal relationships. The question of what happens in care relationships is an area of controversy and one of sociological interest. It highlights how medical authority and ideas about how care should occur might influence the informal sphere and the forms of contestations that might occur at the interface of the two spheres. There is a widespread view that HIV and AIDS is a disease that is surrounded by controversies (Schoepf, 1991; Powell-Cope and Brown, 1992; Annas, 1999; Fombad, 2001). Imposing confidentiality on the local cultural systems without considering the values of the people may be viewed as Eurocentric and insensitive especially to the interests of the family caregivers.

There is evidence that there are illness situations which render exclusive communication between the patient and medical practitioner inappropriate. A study by Glaser, Rubin and Dickover (1990 cited in Haug, 1994) revealed that poor communication between the caregivers and the physicians led to the former expressing displeasure with physician support in solving care problems. Haug (1994) recognizes the value of expanding the healing relationship to include the family caregivers of the elderly with dementia illnesses. A study which compared the interaction of a cancer patient with the physician when a family member was present and when patients were without a family member (Labrecque, Blanchard, Ruckdeschel and Blanchard, 1991) showed that when illness was serious, interaction between the patient, the doctor and the family was crucial. They established that irrespective of their age and sex, cancer patients were likely to be accompanied by a family member when they had poor performance status, undergoing active treatment and faced uncertainty and anxiety because of treatment failure, recurrence of symptoms and progression of disease. Family members provided emotional support and their presence influenced the quality of interaction as the physicians were likely to provide more information pertaining to treatment and the patients' medical status. The caregivers also benefited from the consultation. They considered provision of information a form of social support and it alleviated their uncertainty. The information addressed the family members' concerns about the symptoms-related problems and existential issues especially fear of the future. Given that presence of a family member in a medical encounter may be viewed as an indirect measure of the seriousness of the illness, it follows that the caregivers may be frustrated by restrained transmission of information by the doctor during medical encounters. And a situation whereby a disease is treated with confidentiality amidst severe symptoms is likely to affect caregiving experiences negatively because essential information is withheld.

It is reasonable to uphold confidentiality to protect people living with HIV and AIDS from pervasive stigma which makes them vulnerable to being isolated (Corey, Corey and Callanan, 2003), but also because privacy is integral to human dignity (Wright, 1987). But societies should equally be concerned about possible disintegration of the very relationships which have thus far contributed to orderliness by relieving the hospitals of the burden of health care as a result of the epidemic. Colledge and Maddison (1992) observe that informal caregivers may develop negative feelings when they are not provided with sufficient information about the patient. This is because

> ...they take responsibility for the welfare of the patient and feel that they should be told what treatment is being given, how the illness is progressing, etc. This could, of course, cause conflicting demands on the medical staff if the patient does not want this information to be shared (Colledge and Maddison, 1992: 76-77).

This suggests that the expectation is perceived negatively by those who feel that they deserve to know. Rajaram (1997) suggests that both patients and caregivers who manage chronic illnesses should be provided with comprehensive information about the physiological and psychological aspects of the treatment strategies. Some African scholars, who also subscribe to the idea that confidentiality is a fundamental right, have identified dilemmas that may arise in the context of HIV and AIDS informal care (Fombad, 2001; van Dyk, 2001; Jackson, 2002). This is because once medicine has retreated the lay people may find themselves dealing with the unknown.

In Africa, this practice is peculiar because family members are usually part of the medical encounter – present with an adult patient in a consultation room when the doctor makes diagnosis. They may be consulted during the diagnostic questioning of the patient and when instructions about prescription and further diagnostic tests are given (Andersen, 2004). Similarly, a cross-cultural study of how families adjusted to cancer reported that less than 40 percent of the physicians in the survey from a number of regions including Africa, disclosed cancer diagnosis to patients yet almost all of them disclosed it to some family members (Holland, Geary, Marchini and Tross cited in Gotay, 1996). Gotay argues that "[T]he family members are the 'guardians' of the information, which requires a great deal of effort by the family to keep the diagnosis from the patient" (Gotay, 1996: 39). Harris, Shao and Sugarman (2003) also established that despite the cancer stigma in Northern Tanzania, there was high involvement of the family members in the disclosure process. They observed that while medical ethics emphasized confidentiality, physicians observed it in the case of HIV and AIDS diagnosis but not for cancer. They argue, "The fact that AIDS is a sexually transmitted disease and that it is more stigmatised than cancer may account for the participants' differential sensitivity to confidentiality related to disclosure about cancer and AIDS" (Harris et al, 2003: 911). Some of the physicians were open to familial decision to withhold disclosure of the diagnosis completely from the patients while others relied on the family for assistance in making such disclosure. These practices may be seen as ways in which biomedicine adapted to the cultural values of communality and sharing, what may be termed 'Africanization of biomedicine' (borrowing Finkler's, 2004 term of 'Mexicanization of biomedicine'). Failure to share diagnosis and prognosis with family members is deviation from a cultural norm which biomedical practice observed for a long time in Africa.

Haug (1994: 9) concludes that scholar "still know very little about doctor/patient/caregiver relationships in terms of the characteristics of the players, content, processes such as initiations, terminations, conflicts, or accommodations, and health outcomes". It is critical to study these relationships in the context of HIV and AIDS home-based care.

Home-based care

Generally, care becomes a goal in areas where cure does not have primacy and the need for care is long-term, that is, when illness is incurable, chronic or terminal (Kuhse, 1997; Twigg, 1998). In such situations, medicine relegates the care responsibility to the private sphere because the dual nature of caring – "labour and love" (Graham, 1983) renders it a gendered activity and a family responsibility (Thomas, 1993).

According to Woodward, Alelson, Tedford and Hutchison (2004) home care entails "the provision of an array of health and social services designed to support living at home" and it is primarily provided by relatives, friends and neighbours who are identified as 'carers' or 'caregivers' (Thomas, 1993; Thomas, Morris and Harman, 2002; Heaton, 1999). Describing home-based care in the context of HIV and AIDS various writers indicate that it is care that takes place at home with the support of relatives (Uys (2003; van Dyk, 2001; Chimwaza and Watkins, 2004), in order to complement or substitute professional care. It is emphasized however, that when it is necessary hospitalization should be made available. In fact, Uys (2003) identifies hospital, out-patient and community home-based care as the three components of AIDS care. Tronto (1993) advocates care that is sufficiently integrated and indicates the relevance of the degree of integration in assessing the care needs. Through integrated home-based care, it is possible to provide comprehensive care which includes clinical management, nursing care, economic, psycho-spiritual and social support (Defilippi, 2003; Cyrus 1979; Hailperin, 1979). As an approach to care home-based care ideally presupposes collaborations between the various providers of care such as the state, the voluntary sector and the family.

Increasingly, sharing the responsibility between the private and public domains has become the guiding value though the question of how much should be done by each remains critical (Davies and Robb, 1998). For example, some argue that the idea of social care necessarily reflects imbalances between public and private responsibility in the provision of care whereby the latter assumes more tasks under community care (Dorn, Henderson and South, 1992). Twigg (1998: 273) also suggests "welfare states differ in the degree to which they regard social care as a private as opposed to collective responsibility: and that boundary is differently drawn…" But it is also obvious that it is the mandate of planners to draw such lines. Firstly, there is policy shift globally regarding health care provision in that states are increasingly devolving the responsibility from institutions to communities (Horwitz and Reinhard, 1995; Heaton, 1999). Toseland et al (1995: 518) summarize this movement as follows:

> Trends in health care such as efforts to reduce hospital stays, to treat aspects of serious illnesses on an outpatient basis, and to provide terminal care in home and community settings, are likely to increase the role of family members as caregivers of cancer patients in the future.

This has inevitably led to the private sphere in the form of home and informal relationships in communities and primarily families being important resources for care (Horwitz and Reinhard, 1995; Twigg, 1999; Cowen, 1999; Yamamoto and Wallhagen, 1997; Heaton, 1999; Mupedziswa, 1998; Sevenhuijsen, 2003; Uys, 2003; Watt, 2002; Williams, 2002; Woodward, Abelson, Tedford and Hutchison, 2004). Williams (2002) uses the construct of 'the changing geographies of care' to explain this development in Canada whereby the home is considered the primary place of care for patients. These changes are achieved through several policy measures which aim at retaining ill people at home. For example, Davies and Robb (1998: 4) note that although caring straddles the public and private spheres, "the majority of health and social care is carried out on an unpaid basis in the home..." In some places where filial obligation towards the elderly is a widespread norm, the growing need for care has been responded to through provision of formal services that are meant to support the families (Yamamoto and Wallhagen, 1997; Alelson, Tedford and Hutchison, 2004).

The social, economic and medical factors have contributed to these changes following a period when hospitals and other state financed institutions predominated in the provision of care. The developed societies saw rapid increases in the number of people aged above seventy years in the post World War II period. Many elderly people develop chronic illnesses and become frail thus necessitating care by others. Woodward et al (2004) attribute the rapid growth of the home-care sector in Canada to two factors in addition to longevity: aggressive discharge planning and shorter stays in hospitals due to financial constraints that hospitals faced in the 1990s and an increase in the number of people with chronic illnesses and physical disability. Nilmanat and Street (2004) indicate that due to the inability of hospitals to provide beds, the Thai government adopted community-home based care for AIDS patients. The negative image of institutions of care also makes them less favourable while community and home care remain popular (Higgs, MacDonald and Ward, 1992). A recent study by Dworzanowski (2002) on hospice care in South Africa established that less than 1% of the population living with AIDS in South Africa obtained care from hospices and this is an insignificant proportion of the people who are ill because of the disease. Similarly, Lesotho has not been insulated from these global trends and the adoption of community home-based care was a response of to the increased care burden on the public hospitals (Ministry of Health and Social Welfare, 2002).

In sub-Saharan Africa, the burden of providing health care for long-term incurable illnesses is attributed to the HIV and AIDS epidemic with its unprecedented levels of adult morbidity (Barnett and Whiteside, 2002; Mupedziswa, 1998). Mvududu and McFadden (2001:113) indicate that "the spread of HIV/AIDS has aggravated the health crisis with most governments trying to cut down on health expenses by encouraging home-based care" which is mainly the responsibility of women. In sub-Saharan African countries the problem is compounded by inequalities, poverty and poor health service delivery. Due to the imperatives of the structural adjustment programmes the states 'rolled back' such that "access to medical care has diminished" (Baylies, 2002: 617). Consequently, the limitations of scientific medicine which Western societies realized in the late twentieth century (Lupton, 1994) became a serious problem for poor countries in the era of HIV and AIDS because many governments adopted prevention and care policies which deemphasized antiretroviral treatments - the 'relatively high level care' that is inclusive of HAART (Nattrass, 2004). The neo-liberal fiscal policies generally led to reductions in governments' expenditure on the social sector including health and to decline in the quality of life and human development (The Independent Commission on Population and Quality of Life, (ICPQL) 1996; Mwanza, 1999; Fawole, 1997) and these declines were exacerbated by AIDS.

The primacy of economic considerations is noticeable in the provision of medical care for PLWHA. The competing criteria of 'cost' and 'care' as they affect decisions on rationing and whether patients should be cared for in hospitals or at home as well as the forms of regimens they should obtain cannot be ignored. Although doctors maintain high autonomy in the day-to-day decision-making processes, they do so taking into account the broader political and economic factors in society. As Johnson (1993: 148) indicates,

> The general sphere of politics in modern society has the capacity to expand and contract. In periods of social change, including political reform, arenas of decision making once considered realms of neutral, objective fact may be reconstituted as politically contentious. That is to say, matters of purely technical concern – to be resolved by recognised experts – erupt into political controversy.

Glannon (2004) and Gross (1998) indicate that provision of health care involves rationing of scarce medical resources guided by efficiency and fairness. The co-existence of state 'rolling back' and what may be viewed as "demedicalisation" and emphasis on "holistic health" (Lowenberg and Davis, 1994) in HIV and AIDS care, whereby for almost two decades of the epidemic antiretroviral drugs were not available in the public health care sectors in most badly affected countries including Lesotho, may not be coincidental.

Therefore, claims that patients gravitate towards home care may only be viewed as rhetoric; especially in the case of AIDS care in the 1990s and beyond it is obvious that hospitalization is deliberately curtailed. There is substantial evidence that non-institutional care is cost-effective on the part of governments (Rossman, 1979; Thomson, 1998; Mupedziswa, 1998). Rossman indicates that "[h]ome care is a good deal more economical than hospital care, and documentation exists that home care programs save needed hospital beds or cut down on the duration of hospitalization" (Rossman, 1979: 63). However, the long-term impacts of HIV and AIDS on societies suggest that this view is myopic because without comprehensive response programmes which include among others, the HAART, debilitating illness and demand for hospitalization remain high. Nattrass (2004) provides a systematic analysis showing the inadequacy of such a form of treatment in South Africa and its failure to prevent recurring hospitalization, further viral infections and early deaths, and therefore its cost-ineffectiveness. But it is equally true that home-based care is used to avert frequent and long-term hospitalization, thus lowering costs in the public health sector even though it may not be clear how attempts to balance care and economic obligations are experienced by family caregivers.

Secondly, at the micro level, feminist research addresses the question of who provides informal care in society. It builds on the notion that informal care is a gendered practice that is embodied in women's labour (Bury, Morrison and McLachlan, 1992; Daly and Lewis, 2000; Finch and Groves, 1983; Finch, 1989; Graham, 1983, 1991; Thomas, 1993; Twigg, 1990; McKie, Gregory, and Bowlby, 2002). For instance, Bury, Morrison, and McLachlan (1992: 29) state: "caring is an activity which is seen as natural for women. Traditionally women have been seen as caregivers because of their inherent capacity to nurture others". This essentialist view is also expressed by Warren (1990) who equates the skill that the 'home helps' of the elderly in her study had to their role as women and mothers at home. Two particular sources of this debate are identified as Finch and Groves' (Morris, 1998) and Graham's research in the late 1970s and early 1980s, respectively. For instance, McKie et al (2002: 901) point out that the idea that women are inevitably carers is succinctly captured by Graham (1983):

> Caring is 'given' to women: it becomes the defining characteristic of their self-identity and their lifework. At the same time, caring is taken away from men: not caring becomes a defining characteristic of manhood.

In Britain, feminist research critically assessed the policy trends towards deinstitutionalisation which became apparent throughout the 1980s and 1990s. It suggested that the women's care burden was being doubled and their oppression and economic dependence on men worsened (Davies and Robb, 1998).

This research led to the visibility of carers and informal caring in public policy (Heaton, 1999), however it is also biased. For instance, there is overwhelming evidence that both men and women are carers (Arber and Gilbert, 1989; Thomas et al, 2002; Toseland et al, 1995; Sevenhuijsen, 2003) and capable of caring (Tronto, 1993). Davies and Robb (1998) criticise the scholarship on several grounds: for emphasizing the burden of care and neglecting its pleasures, focusing on carers and not the recipients of care, focusing on the female carers though there were also male carers and reflecting the interests of the privileged class of women. Similarly, Warren (2003) concludes that in Britain the female-carer was a predominant phenomenon even though there were class differences with women working in manual jobs contributing more hours of care than their professional counterparts. These formulations of care have been challenged by other feminists as alienating women in a role that some may be both willing and prepared to perform as they may find enrichment amidst the stress of providing care (Lloyd, 2001).

Family caregiving experiences in chronic illness

HIV and AIDS illness is a chronic condition. Availability of relatively effective medications that reinstate health and facilitate functional existence for people with the HIV infection means that the AIDS-related illness can be defined as chronic. This conceptualisation is general yet it is only fully realised in contexts where the antiretroviral (ARVs) drugs are available as both morbidity and mortality decline significantly (Guest, 2003; Nattrass, 2004; Persson, 2004). Importantly, this categorization has implications for provision of care and management of illness even when the medical interventions are minimal and drugs lack pharmacological attributes to subdue the HIV, because some of the opportunistic infections can be life-threatening. It means that the responsibility to manage the symptoms and ensure the quality of life of the patient partly belongs to medicine and partly to the patients and their families. Therefore, irrespective of the chronic status of HIV and AIDS being relative, hospitalisation periods are curtailed while families contribute to care substantially. Conrad and Bury (1997) refers to Anselm Strauss, one of the major contributors to the study of chronic illness, who recognized that not only the sick person is affected in chronic illness but that families provide a great deal of caregiving by doing work to or for the chronically ill person. The diagnosis of a life-threatening disease such as cancer "is an event which forces the cancer patient to rely more on family resources, and therefore, affects the family as well as the patient" (Bloom, 1996: 53).

The conceptualisation of chronic illness includes the recognition that everyday life is disturbed when a family member is diagnosed with a chronic disease (Bury, 1982, 1991, 1997; Carricaburu and Pierret, 1995) and that family members as the primary source of social support have to reorganise their lives to accommodate the disruptions caused by illness (Bury, 1982; Hyden, 1997; Conrad and Bury, 1997; Nilmanat and Street, 2004). Carricaburu and Pierret (1995) indicate that the disruption occurs in three areas: the everyday taken-for-granted assumptions and behaviours including commonsense boundaries become violated, the commonly used explanatory systems become challenged and individuals are forced to rework their biographies and identities, and lastly, it becomes necessary to respond to the new situation by mobilising resources. Scambler (1989) too, observed that the family and patients were thrown into disarray when a member became ill from a stigmatizing or disabling chronic illness such as epilepsy; tension and conflict emerged as they reconstituted their life to restore equilibrium. Davis, Davis and Dowler (2004) reiterate the point that illness leads to disruptions as social relationships and life-paths are interrupted.

The dominant perspective on caregiving experiences emphasises the negative impacts of chronic illness on the domestic sphere (Aneshensel, Pearlin and Schuler, 1993; Packenham, Dadds and Terry, 1995; Land and Hudson, 2002; D'Cruz, 2002; Tolliver, 2001; Litt, 2004). Most studies stress the negative impacts of caregiving when illness is protracted. Caregiving for the elderly with chronic diseases has been associated with difficulties in such areas as finances, social well-being, and psychological problems such as depression, guilt, shame, frustration and stress (Bond, Clark and Davies 2003). Horwitz and Reinhard (1995:139) identify two aspects of caregiving as "caregiver duties and caregiver burden". The former is the activities and responsibilities of the caregiver. The latter refers to the negative outcomes of providing care for chronically ill family members. Zarit, Todd and Zarit (1986) defined caregiver burden as "the extent to which caregivers perceived their emotional or physical health, social life, and financial status as suffering as a result of caring for their relative" (quoted in Yamamoto and Wallhagen, 1997:164).

Caregiver burden is viewed as one of the major experiences of carers (Chimwaza and Watkins, 2004) and it may also affect other spheres of life of the carer beyond the caregiving role. This situation is illustrated by Pearlin, Aneshensel and LeBlanc (1997) through what they referred to as "stress proliferation" – a phenomenon that marks expansion of initial stressors or emergence of stressors in areas that were initially stress-free thus leading to an accumulation of stressful factors. Their framework distinguishes primary stressors from secondary stressors. The former entail the stressors which emanate from the actual performance of tasks in activities of daily living (ADL) and include both the objective and subjective assessment of the caregivers about their caregiving situation. The latter arise as a result of providing care but do not arise directly from performing the caregiving tasks or duties. The caregivers feel overloaded if they encounter hardships in their role and the "chronic and progressive nature of AIDS is a prime mechanism behind the expansion of stressors among AIDS caregivers" (Pearlin et al, 1997: 233). Other mechanisms through which stress in AIDS caregiving unfolds include the context and background characteristics of caregivers such as being gay, HIV positive status and consciousness of stigma (Wight, 2000) and the influence of primary and secondary stressors on the physical health of caregivers (LeBlanc, London and Aneshensel, 1997).

Pakenham, Dadds and Terry (1995) indicate that the burden is interactive and arises as a result of incongruence between the patient's demands and the needs of the carer. However, the demands or expectations of the care-recipients on the carer may not be physical only.

Their findings from a study of carers of HIV positive individuals reported that "the more instrumental concerns and health complaints a patient reported, the more likely his carer was to experience high levels of caregiving burden" (Pakenham, Dadds and Terry, 1995: 196). Another interesting finding was that caregiving was more psychologically than physically burdening. They established that the caregivers experienced more burden when the patients were asymptomatic than when they were dealing with specific health problems. Magliano, Fiorillo, De Rosa, Malangone and Maj (2005) suggest that different pathologies will affect the caregivers in different ways depending on their symptoms and the social reactions to such diseases. The tendency of HIV to affect all body systems including the brain is also observed by Bowers (1996). These situations are expected to complicate caregiving especially when information about diagnosis is not shared openly for fear of stigmatisation.

Besides, caregivers involved in HIV and AIDS care encounter some unique challenges. Some of the caregivers may have to provide care while they are also seropositive and in some cases experiencing decline in their own health (D'Cruz, 2002; Land and Hudson, 2002; LeBlanc, London and Aneshensel, 1997; Wight, 2000). Levine (1991: 51) argues that "AIDS throws families into crisis". Levine quotes Gary Lloyd (1988) who showed that "families with a member discovered to have HIV infection or diagnosed with AIDS will experience high levels of stress, and disruptions in all areas of family life" (Levine, 1991: 52). These impacts are associated with the demographic aspects of HIV and AIDS infection and related illness, the high dependence of the infected individuals on the family for support and care, the social stigma and isolation of the affected families, the risk of infecting other family members and the implications for care (D'Cruz, 2002).

In low income households, the burden is compounded by material hardships. Studies on sub-Saharan Africa illustrate that the family members experience stress and financial burden as a result of caring for relative infected by HIV and AIDS (Ankrah, 1993; Baylies, 2002; Bindura-Mutangadura, 2000; Chimwaza and Watkins, 2004). Seeley, Kajura, Bachengana, Okongo, Wagner, and Mulder, 1993) argue that as a result of protracted sickness, household resources are eroded and families are burdened as their capacity to provide care is gradually diminished by AIDS illness. Uys (2003) argues that due to family caregivers' lack of the essential skills, knowledge and emotional support, caregiving becomes extremely challenging. This occurs because by shifting the care responsibility to families and communities authorities are likely to disregard the plight of HIV and AIDS patients and their families (Mupedziswa, 1998). While the impacts of HIV and AIDS on the family have received attention in research, the experiences of the individuals who provide AIDS care are less understood. Tolliver (2001: 145) indicates that family caregivers are the "hidden victims" of the epidemic.

The idea that diagnosis of chronic illness affects the family as a unit disregards confidentiality but is consistent with the conceptualisation of stigma. In assumes that care is provided on the basis of medical diagnosis yet in case of stigmatised disease, family caregivers may be less informed. Powell-Cope and Brown (1992) and Poindexter (2005) considered how family caregivers went about disclosing that they were providing care to persons with HIV and AIDS. However, Siegfried (September 2005) reported that some patients disclosed their HIV-positive status to the volunteer caregivers but not to their families for fear of stigma and indeed caregiving relationships may be characterised by anger and resentment especially among spouses as a result of knowing about the HIV and AIDS positive status of the care-recipients (D'Cruz, 2002). According to Goffman's conceptualisation of stigma, caregivers share in the experience with the patients because stigma is not confined to the individuals who bear the 'discredited' or 'discreditable mark'; it has the tendency to affect their associations (Goffman, 1963) and 'associates' may avoid or terminate social relations with stigmatised individuals. This means that stigma may also be a factor in the life of those who are related to the affected individuals thus compelling them to negotiate their everyday social interaction as if they also possess the discredited mark. Goffman (1963) termed this phenomenon courtesy stigma. Family members of HIV seropositive individuals (D'Cruz, 2002) and of individuals with Alzheimer's disease may experience courtesy stigma and isolation (MacRae, 1999). Roldan (2003) showed that for fear of shame, isolation and the negative implications of destructive gossip (*bochinche*), Puerto Rican family members would collude with the infected individual to keep the HIV diagnosis secret. However, courtesy stigma has ambiguities in the sense that one may not be fully acceptable to the stigmatised individuals even though they may generally be treated as part of them (Goffman, 1963).

The criticisms against this body of literature vary but the key ones are, firstly, that these studies over-emphasize negative experiences as outcomes of caregiving (Yamamoto and

Wallhagen, 1997; Prout, Hayes and Gelder, 1999; Berg-Weger, Rubio and Tebb, 2001; Sherrell, Buckwalter and Morhardt, 2001) and also understate the contexts in which caregiving is embedded (Moen, Robison and Dempster-McClain, 1995). Moen, Robison and Dempster-McClain (1995) call it the 'role strain perspective'. Yamamoto and Wallhagen (1997) indicated that the influences of family caregiving on the carers may not be easily reduced to narrow constructs such as 'caregiving burden'. In a Japanese study on why family caregivers would continue the care of the elderly with dementia despite hardships, they identified the *value of care* characterised by strong cultural norms regarding family caregiving and interpersonal relationships which made it possible for women to provide care to the elderly parents amidst the difficulties.

Secondly, caregiving research is criticised for obliterating the care-recipient and highlighting the carer as the subject. This issue is raised within the disabled people's movement which essentially questions feminist theories of care which exclude the experiences of the disabled people (Lloyd, 2001; Morris, 1993, 1998; Hughes, McKie, Hopkins and Watson, 2005). Although the current study also focuses on the caregivers, it attempts to include the care-recipient as an important part of the context of caregiving experiences and examines the descriptions of the caregivers in relation to the cared-for in detail. This is because caregiving as an element of the care process entails social interaction between the cared-for and the caregiver and it involves intersubjectivity (Wagner, 1983). In AIDS care, women caregivers suffer physically and emotionally thus making them particularly vulnerable in the face of the epidemic (Akintola, 2006).

Recent work (Bury, 1991) sheds light on the usefulness of approaching chronic illness with an open mind and perceiving adaptation and management of symptoms as part of the lived experience in illness. Similarly Prout, Hayes and Gelder (1999) in a study on how families managed childhood asthma found that the 'impact' or 'burden' were overcome by suitable strategies that families adopted in order to adapt to the prevailing conditions and make sense of them. They also identified availability of suitable medications as a catalyst in their participants' experiences. Likewise, Berg-Weger, Rubio and Tebb (2001) in a study of the caregivers of the elderly suggest that adopting a "strength-based approach" gave insight into the positive aspects of caring. They used the constructs of 'caregiver adjustment', 'competence' and 'spiritual connection' to highlight some of the caregivers' positive experiences and concluded that caregiving could be both a rewarding and a difficult experience. Tolliver (2001), and Powell-Cope and Brown (1992) concluded that in addition to the daily stressors - depression and frustration - the carers also realised social and personal benefits such as a sense of empowerment and activism in HIV and AIDS-related activities.

The body and its care in chronic illness

Physical care necessitates attention to the corporeality through medicine, food, touching and maintaining hygiene. Apart from the attention bodies receive through provision of personal care, it is a fact that social interaction is mediated through human bodies (Goffman, 1963; Kelly and Field, 1996; Lock, 1993; Weinberg and Williams, 2005; Persson, 2004) meaning that care as relational responds to the bodily readings which carers make from time to time. As Lupton (2003) asserts HIV and AIDS has resuscitated the old imagery of the body as a rich text from where disease presence may be interpreted, a situation which is attributed to failure by medical technologies to help the body conceal the HIV throughout the illness.

Kelly and Field (1996) suggest that the study of chronic illness should make the body its project. In chronic illness the body undergoes radical changes thus becoming the focal point of the patients' and their family members' experiences (Lawler, 1998). Hence, caring for the chronically ill individuals is primarily about caring for the bodies whose level of independence may be intermittently or constantly limited. Caregiving entails coping with the realities brought by the illness including debilitation. Kelly and Field (1996: 247) argue that,

> At the very epicentre of the coping experience and from which other social coping processes flow, is the management of the physical problems which the chronic illness generates. The physical aspects of living such as eating, bathing, or going to the toilet are the prime focus of the experience of chronic illness, because above all else coping with chronic illness involves coping with bodies – not just for people who are chronically ill themselves but also for their families and familiars.

They further stipulate the various ways in which the biological and physical aspects of the body as dimensions of the self and identity are sociologically significant, and how they become transformed by illness and other processes such as aging. Phenomenological accounts on the effects of changes in embodiment on the subject and its relationship to society (Sacks, 1987) demonstrate the significance of one's physical constitution for the self.

Caregiving activities are meant to arrest or resolve bodily dysfunctions and these activities entail social interaction which is mediated through bodies.

Turner's (1984 cited in Frank, 1991) conceptual framework identified four dimensions of the body and integrated them with different institutional subsystems in society. The body is theorised according to four tasks or sub-problems which society must resolve: *reproduction* and *regulation* of populations on the one hand and *restraint* and *representation* of individual bodies on the other. The model connects these tasks to different institutional subsystems in society in which each task is handled. Relevant here are society's task to the body's interior and exterior regarding restraint and representation, respectively (Frank, 1991: 43). The significance of Turner's model lies in the realisation that the relationship between the body and society is reciprocal: As Frank (1991: 45) states, "What we have in Turner's categories are not only four tasks which a society must solve with regard to bodies, but also four problems which a body must solve to be in society". Kelly and Field (1996) suggest that "to be acknowledged as competent social performers we have to be able to give impression of some degree of control, use and presentation of our bodies" (p. 246). Loss of independence, autonomy, mobility and control of bodily processes as a result of disability and terminal illness in contemporary societies produce inconsistencies in individual embodiment (Weinberg and Williams, 2005; Lock, 1993).

Frank (1991) suggests an approach that recognises that "the body is a problem for itself" and that bodies have tasks which are determined within social contexts and define embodiment within these contexts. His model of four ideal types of bodies: the disciplined body, the mirroring body, the dominating body and the communicative body (Frank, 1991) is considerably useful in the context of chronic illness and caregiving. For example, it would appear that the caregivers and the care-recipients would predominantly represent different types of bodies. Ironically, although caring for the body of the patient through feeding is basic to survival (Telfer, 1996; Mepham, 1996) and bathing is meant to restore the dignity which is a concern among the terminally ill (Chochinov, Hack, McClement, Krstjanson and Harlos, 2002) and maintain orderliness because as Seymour (1998: 166) argues, leaky bodies pose danger to social order and threaten maintenance of boundaries, it is most likely to be intrusive.

The literature on formal and informal care shows that taking care of others' bodies may not be experienced with detachment (Lawler, 1998; Lawton, 1998; Twigg, 1998, 1999; Lupton, 2003). In particular, empirical studies indicate two factors that may affect care for others' bodies as cultural meanings concerning the integrity of the body as well as privacy and tactility. Lawton (1998) indicates how bodily 'unboundedness' – vomiting, incontinence and emission of other bodily fluids – among terminally ill cancer patients evoked feelings of incompetence among family carers and influenced decisions to institutionalise the patients. Even in hospice such bodies are negatively perceived hence their sequestration:

> The negative reaction which carers and other participants within the hospice exhibited towards unbounded patients can perhaps be understood in terms of the capacity of the unbounded body to breach and percolate their own body boundaries. The smells, and other fluids and matter emitted from the unbounded body, extended the boundaries of the patient's corporeality, such that the patient's body 'seeped' into the boundaries and spaces of other persons and other places (Lawton, 1998: 134).

Twigg (1999: 381) pursues the notion of privacy and notes that bathing and washing are normally done privately and single-handedly in designated areas within the home but disability disrupts these ideals of privacy and they bring about a new social ordering. She further indicates that the body, just as the home, is organized spatially according to degrees of privacy. The carers in her study observed this ordering when they touched the bodies of older people such that they avoided washing their private parts but touched their backs and other hard to reach parts such as feet without constraint. This is observed in order to avoid embarrassment and humiliation. As Lupton (2003) indicates, such constraining conditions necessitate help by others for activities which are necessarily private, thus leading to awkward situations whereby the social rules of touching and showing the body parts are contravened.

Lawler (1998) also reported the challenges encountered by newly-trained female British nurses who felt inhibited when it came to seeing and touching naked bodies of male patients and attributed their feelings of incompetence to their non-touching culture. Nursing disrupted the typical male-female relationships in society. Synnott (1993) identifies the western societies as non-tactile compared with the non-western cultures, a phenomenon that is attributed to increasing impersonality in modernity. However, in the non-western societies too there are cultural rules such as rules of avoidance which guide relationships between kin members who are related differently and for whom touching may be prohibited. Besides, even within close family relationships touching boundaries are defined by age, gender and nature of relationships. Similarly, touching across gender lines is tolerable in the context of sexual relationships or in formal health care contexts. Therefore, informal caregivers in most cultures have to deal with taboos concerning body touch.

The reviewed literature shows that there are major shifts globally from institutionalised to home-based care, mainly as a result of declined economic capacity of states to cope with increasing demand for long-term care and ideological choices which affect policies on care. These changes contribute to how doctors provide medical care thus making care less apolitical. Especially in the era of HIV and AIDS, difficult decisions regarding how to meet the care needs of the sick have generated debates while the home sphere is used as the safety net for responding to the needs of patients who may be inadequately provided with medical care. Since illness and disease occur in the context of bodily changes, care for the chronically ill entails paying attention to the body. The study of caregivers' experience using the phenomenological approach should elucidate what the caregiving process means to those who provide care within a unique context of confidentiality, stigma, secrecy and limited medical care. Chapter Three outlines the methodological approach, the characteristics of the caregivers and their caregiving situations.

CHAPTER THREE

METHODOLOGICAL APPROACH AND SAMPLE DESCRIPTION

This chapter discusses the procedures and techniques that were used to obtain the data needed to describe the experiences of the family caregivers who provided care for the chronically ill patients who were in home-based care and were diagnosed with HIV and AIDS-related illnesses in Lesotho before the government introduced ARVs in the public health sector. It was meant to document what they experienced in caregiving and how they experienced it. The study adopted phenomenology as a philosophical and theoretical approach to understanding the meanings that people had about their everyday life as caregivers from their own perspective. The chapter describes the phenomenological approach and how it was used to study caregiving experiences in a care environment largely characterised by confidentiality. It also describes the procedures followed to identify the study participants, their characteristics as well as the nature of the caregiving relationships. Finally, it illustrates how the descriptions about caregiving were collected using the *epoché,* how the interview data were captured and analysed, definition of key concepts as well as the ethical considerations and limitations of the study.

The phenomenology approach: the theory and method

Generally, the qualitative approach, as a way of approaching the empirical world is guided by the phenomenological understanding of the social world. The German philosopher, Edmund Husserl (1859-1938) is considered the founder of phenomenology. Husserl's phenomenology criticized the modern natural sciences and positivism, for having distanced themselves from their foundations in everyday life, and being preoccupied with producing the abstract world which pays little attention to the ordinary human experiences upon which it is based. As Alvesson and Sköldberg (2000) indicate, when phenomenology was launched in the early 20th century its slogan – *to the things themselves* – "signalled a return to the concrete sensuous everyday life world which positivism, with its rational 'scientific' analyses, had drained of all its substance and colour, leaving behind mere abstract formal structures, castles in the air set free from their earthly moorings" (Alvesson and Sköldberg 2000: 36).

Phenomenology is a firm acknowledgement that the natural and social worlds are unequivocally different, with meaningfulness of social phenomena to the members of the social world being emphasized (Smart, 1976).

Alfred Schutz is considered the founding figure of social phenomenology. He focused on the way members of society characterized the world of everyday life and how they produced meaning from social interaction (Wagner, 1983; Cresswell, 1998). Schutz has profoundly influenced social phenomenology and laid foundation for some of the popular theoretical perspectives in sociology such as ethonomethodology which are concerned with meanings – norms, values and beliefs (Craib, 1992). However, Schutz did not develop specific methodological procedures for conducting inquiry on how members of society constitute everyday life. This has led to a serious weakness in sociological inquiry whereby it is common for researchers to assume that phenomenology is synonymous with qualitative research. Therefore, this study mainly adopted the principles that have been used to guide phenomenological inquiry across various disciplines: religion, social psychology, anthropology, education and nursing. The usefulness of the guidelines provided in these writings lies in their consistency irrespective of disciplinary focus.

Methods and Data

Research design

Cresswell (1998: 65) indicates that "phenomenology is used to understand the essence of experiences about a phenomenon". The phenomenological approach studies the description of the lived experiences and meanings according to the perspective of those who have experienced the phenomenon under investigation. This study sought to understand the 'lived experiences' of the caregivers by exploring their descriptions of their world of caregiving – the meanings they attached to the caregiving role as an aspect of their reality (Wagner, 1983; Taylor and Bogdan, 1984; Worthen, 2002). A qualitative research methodology was found appropriate because the research goal was to understand the experiences about home-based caregiving from the participants' perspective. The broad question which the study pursued was: *what are the experiences of family caregivers in Lesotho when caring for a chronically ill family member,* *who has been diagnosed with HIV and AIDS, in the home setting?* The research design was appropriate for answering the research question (Bryman, 1988; Mouton, 2001) and was consistent with the assumptions about how the everyday life of caregiving could be studied without imposing the perspectives of the 'objective' researcher and sociological constructs on it, which are critical in phenomenology because the subjects of study must describe the object of their experience as it appears in their consciousness. Some of the characteristics of research objectives that dictate the use of the qualitative approach are: first, to capture the descriptions of the lived experience and create meanings from it, and second, to generate studies that capture the subjective perspectives of the study participants (Roldán, 2003; Wisker, 2001).

Phenomenological research is "an attempt to understand empirical matters from the perspective of those being studied…, serves as the rationale behind efforts to understand individuals by entering into their world of perception in order to see life as these individuals see it" (Riemen, 1998: 275). As various scholars have indicated, the aim of the phenomenological method is

> to determine what an experience means for the persons who have had the experience and are able to provide a comprehensive description of it. From the individual descriptions, general or universal meanings are derived, in other words the essences or structures of the experience (Moustakas, 1994: 13).

Data collection

The phenomenological method is concerned with the exploration of human experiences and it is interested in the social world that is created as a result of what happens in consciousness (Alvesson and Sköldberg, 2000). Therefore, the fundamental requirement is to identify several individuals who have experienced the phenomenon being studied. Alvesson and Sköldberg (2000) and Spinelli (1989) point out that experience is the point of departure in a phenomenological description. In this case the family members who provided home-based care for patients diagnosed with HIV and AIDS in the two hospitals in Lesotho were identified as suitable. Their descriptions of the sensory experiences - seeing, listening and touching; feelings and images they had about caregiving constituted the data (Wagner, 1983). The caregivers also reported about their thoughts about and conversations with the health care personnel, the patients and other family members and the impressions they had about them. These descriptions provided detailed data about their experiences.

Gaining Access

Preliminary data collection was conducted in August 2003 in order to understand policy perspectives pertaining to HIV and AIDS in Lesotho. The major fieldwork was conducted from February to August 2004. It was necessary to identify and recruit the people who had already undergone the experience of providing home-based care for their family members for the study. In order to gain access to the field, I obtained letters which introduced me and described the purpose of the study to the key gatekeepers in the field of HIV and AIDS and the administrative authorities in the study area, from my academic advisor at the University of Cape Town. In studies which involve 'safe' research areas such as cancer caregiving, contact with caregivers has been made directly through the care-recipients (Thomas, Morris and Harman, 2002). In the area of HIV and AIDS it has become a practice to contact study participants through relevant health care institutions such as hospitals (D'Cruz, 2002; Mphale, Rwambali and Makoae, 2002). This is because of the human rights and medical concerns to ensure ethical research which maintains confidentiality and protects the people living with HIV and AIDS (PLWHA) and those who are affected from stigmatisation. The health care workers (HIV and AIDS councillor, nurse and assistant nurse) in the Teyateyaneng Government and church-owned Maluti Seventh Day Adventist hospitals helped to identify eligible current caregivers and ex-caregivers within their respective health service areas (HSAs).

They maintained different forms of relationships with the PLWHA and their caregivers under different circumstances such as disclosure and non-disclosure as well as varying degrees of support. Their relationship with the family caregivers was mainly influenced by how much the PLWHA were integrated into the hospitals' care, support and treatment programmes. After agreeing on the criteria for inclusion, the health care personnel identified the potential study participants from their registry using the patients as a reference. Therefore, purposive sampling was used to select the study participants, although the findings are not statistically generalisable, they highlight caregiving experiences in a particular care context. The participants were identified using the following criteria: (a) a current or ex-caregiver who provided care for a family member diagnosed HIV and AIDS positive at any one of the two hospitals, (b) care was provided at home, (c) caregiving was provided after

2002 when the policy on home-based care became pronounced, (d) current caregivers who had already spent time long enough to have acquired experience about what was involved in home-based care, and (e) willing to be interviewed at length using a tape-recorder. The study adopted a strategy similar to Taraborrelli's (1993) study on Alzheimer's carers. She accidentally discovered the value of interviewing current and ex-carers and realized that both provided analytically different perspectives.

The healthcare workers made initial contact with the patients or caregivers in my absence to introduce the study and solicit the caregivers' participation. The study was introduced as research on the experiences of the caregivers with home-based care. For every first visit to the villages, a nurse accompanied me and introduced the study to the village chief using an introductory letter from the district administrative authorities and the caregivers separately. The initial visits mainly served to confirm the suitability of the prospective interviewees, their consent and agree on suitable times and places for the interviews. In all cases, the involvement of a health worker from the hospital added credibility to my study. However, I went alone to interview the participants. Each interview was preceded by a confirmation by the caregivers that they were willing to participate, allowed the use of a tape recorder during interviewing, understood that the research was part of my training, to give assurance about confidentiality and anonymity in the report and to assure them that they were free to withdraw whenever they felt that they did not want to continue their participation. Two interviewees withdrew after these first encounters.

Interviewing

The data were collected using lengthy interviews. These interviews lasted between one and half and three hours and they spread over two to three days and were tape-recorded. Field-notes on my observations and thoughts about what was going on were written daily following the visits. The interviews generated evidence in the form of first-person descriptions of life experiences in caregiving.

An interview guide which covered broad topics was used in a conversation style with the caregivers. The topics included household structure, kinship relationships in the community, residential arrangements prior to caregiving, how they became involved as caregivers, where the patients sought medical care, what have been their experiences with the health care services, the patients and the illness and what caregiving entailed. However, every interview unfolded in its own pattern. Eventually, the participants talked about their experiences in ways which highlighted the significance of the various events, observations and interactions to them. While the idiosyncratic nature of the descriptions could not be ruled out, the interview data provided understanding on what home-based caregiving for HIV and AIDS patients was. What seemed to be a 'neutral' request: *"I would like you to tell me about what providing care for X involves/d and the experiences you had during your caregiving. Please tell me how it started and how you felt about the different situations",* produced detailed descriptions about interactions, experiences and emotions which the caregivers had, probably sharing them for the first time.

Without leading the interviewees, the focus was on what they thought, perceived and felt about things which they saw, heard and did – things which happened and those which they thought happened. They talked about their actions, social interaction, observations, emotions and meanings of the various situations from the beginning of their caregiving 'careers'. Wolff (2002: 99) notes the characteristics of this approach to interviewing as flexibility, situational sensitivity, open-ended responses and participants' spontaneity. A similar approach was used in a phenomenological study on caring in which clients were requested to describe their emotions and the meanings of their interaction with registered nurses (Riemen, 1998).

In situations where I interviewed current caregivers, I was able to see the conditions of the care-recipients, experience the effects of some of the symptoms which the caregivers described, especially the affliction brought by the pain endured by the patients, their bodily appearance and effects of their loss of control over bodily processes. I also observed some of the less private caregiving activities such as turning the sides, feeding the patients and administering medication all of which could be personally distressing. Some of the study participants indicated that it was good to discuss these issues with someone.

The interviews were conducted at a place of their preference, which was almost invariably the place where caregiving took place – the patient's or their own home – except where caregiving was already exited and the caregivers were at their normal place of residence.

Although it was intended that these would be one-on-one interviews with the caregivers, some of the caregivers invited other family members to the interviews especially on the first day to witness what was being discussed. This could be a way of avoiding possible blame for not involving other family members, especially because it was common to assume at the beginning that I came from one of the various agencies which provided different forms of assistance, including the distribution of food for home-based patients. Information provided in the presence of other family members other than the patients tended to be superficial as there was no probing done at this stage. However, it provided useful prompts for follow-ups and helped towards building rapport. In all subsequent meetings the caregivers were interviewed either alone or in the presence of the patients. Interview times were always adjusted to suit the situation of the caregivers at any time.

Sometimes the caregivers insisted that interviews should be done in the presence of the patients. This could be because they were too ill to be left on their own or they avoided leaving the patient in the dark about what was being discussed which could create unnecessary anxiety. The situation highlighted the sensitive nature of the relationship between some of the caregivers and the care-recipients. The healthcare workers consistently warned me that the area of my research was volatile and needed caution on my part. However, as the richness of the data will illustrate, it did not seem that the presence of the care-recipients led the participants to refrain from sharing their experiences. While this situation could be unusual given that the study did not aim for group responses, it was similar to Merriam's (2002: 58) study: one-to-one interviews could not be solicited because they were incongruent "with the collective, group-oriented culture of Malaysia … Everyone knows everyone else's business, there are no secrets and very little privacy, and nearly all activities involve extended family or community". Of course, the reasons for these arrangements differed.

Interviewing and bracketing

I conducted the investigation in my own society among the people who are affected by the same environment of HIV/AIDS care as me, an environment which I am generally aware of from experience, popular view and literature. It was therefore essential that during data collection I adopted "bracketing" or the "the rule of *epoché*. This is a requirement in phenomenological research, that the researchers specify their assumptions concerning the phenomenon that is being investigated and suspend such preconceptions about the object of investigation (Wagner, 1983; Moustakas, 1994; Cresswell, 1998). This methodological procedure was adopted in order to refrain from the everyday understandings about HIV and AIDS care and to approach the topic 'naively' so that the prejudgments and biases that I had did not influence the interview encounters (Spinelli, 1989: 17; Moustakas, 1994: 33; Merriam, 2002: 94). Merriam (2002) further illustrates that bracketing "allows the experience of the phenomenon to be explained in terms of its own intrinsic system of meaning, not one imposed on it from without" (p.94).

Bracketing was particularly useful in this study for a number of reasons. The field situation was too complex and volatile to be studied with complete openness. First, the health care personnel warned that there was no guarantee that the patients informed the caregivers about their HIV and AIDS diagnosis. Therefore, it was necessary to manage the interviews to ensure that the study did not lead to "unintended disclosure" of the care-recipients' HIV and AIDS status or 'spoil the field'. Secondly, detailed specification of the research question would not only introduce the researcher's preconceptions and categories, it was also more likely to yield unreliable data than the semi-covert approach that was adopted. Calvey (2000) encountered a similar difficulty when studying the culture of bouncers and indicated that it would not have been possible to gain access to undistorted information from the participants because their culture was secretive – a situation that Fielding (1981) confronted in an ethnographic study of the members of an extreme right racist organisation.

Punch (1998) in a paper titled *"Politics and Ethics in Qualitative Research"* highlights the need for researchers to ingeniously assess the situation in the field in order to determine how much should be divulged about the purpose of research. The argument is that although it is unacceptable to habitually use deception and harm research subjects in fieldwork:

> "At the situational and interactional level, then, it may be unavoidable that there is a degree of impression management, manipulation, concealment, economy with the truth, and even deception...Not to do so would unduly restrict observational and qualitative studies" (Punch, 1998: 180).

This approach was significantly facilitated by the phenomenological bracketing or *epoché*. This procedure proved to be useful in two ways: given that home-based caregiving for patients with HIV and AIDS related illness was a common practice, it was possible for the research to scratch the surface by following the assumptions about caregiving as they already exists in the 'natural attitude' – policy documents, lay perspectives, sociological and health literature. Bracketing helped to obtain 'fresh' and detailed depictions of caregiving experiences from the perspective of the caregivers. Also, tackling a sensitive topic in which issues could not be dealt with head-on meant that by my preconceived ideas about AIDS care in Lesotho, caregiving came to be understood "through the voices of the informants" (Cresswell, 1998: 54). The following assumptions were not referred to during the interviews because it was necessary to avoid framing the data:

- The HIV/AIDS status of the care-recipients and disclosure.
- Confidentiality
- Unavailability of ARVs.
- Home-hospital integration in home-based care.
- HIV/AIDS stigma and discrimination of the infected an affected people.
- Caregiving as burdensome.
- Family social support.

Data Analysis

The phenomenological analysis provides a description of the meaning of the lived experiences of several individuals about a common phenomenon (Cresswell, 1998; Angrosino, 2003). Experience is central to this form of analysis and the social scientist focuses on understanding the essence of the experiences.

Data analysis followed the phenomenological method as articulated by different authors (Spinelli, 1989; Moustakas, 1994; Cresswell, 1998; Riemen, 1998; Worthen and McNeill, 2002; Angrosino, 2003). Worthen and McNeill (2002) and Riemen (1998) demonstrate the methodological procedures in their empirical studies on how individuals experienced supervision and caring interactions, respectively. The ideas of these authors were adopted and the following is a description of how the interview data were treated.

1. The interview tapes were transcribed verbatim and this was followed by reading the transcripts individually in order to gain a general sense of the descriptions.

2. Significant statements were pulled out from each transcript, while eliminating repetitive and overlapping statements from the caregivers' descriptions (*horizonalization of the data*).

3. Cognizant of some of the criticisms levelled against the phenomenological method and how data are usually treated, that it condenses the interview transcripts (Miles and Huberman, 1984), the significant statements were retained as elaborate as possible and their contexts maintained by including the details that went with the core statements.

4. Meanings were created by identifying the meaning of the significant statements taking into account the various contexts as articulated in the original descriptions and this was done while maintaining connection between the statements and the original transcriptions.

5. Clusters of meanings were organized into broader themes which retained their various dimensions. This clustering allowed for the emergence of themes or meaning units common to all the caregivers' descriptions.

6. The themes were integrated to bring about a coherent pattern of *what* major experiences occurred in the caregiving career and *how* they occurred.

7. This process of integrating the themes taking into account the contexts and the temporal sequencing of the events as depicted in interviews produced exhaustive descriptions of the various aspects of the caregivers' experiences which were then organised at chapter levels.

8. The descriptions were then examined and interpreted from different frames of references, what Moustakas refers to as "imaginative variation". Understanding of the context of AIDS care in Lesotho and the literature on the factors which affect social care helped to illuminate the experiences. Moustakas (1994: 97-98) states:

> The task of imaginative variation is to seek possible meanings through the utilization of imagination, varying the frames of reference... and approaching the phenomenon from divergent perspectives, different positions, roles, or functions. The aim is to arrive at structural descriptions of an experience, the underlying and precipitating factors that account for what is being experienced; in other words the "how" that speaks to conditions that illuminate the "what" of experience. How did the experience of the phenomenon come to be what it is?

The ultimate impact of a phenomenological study is to provide the essence or central underlying meaning of the experience (Cresswell, 1998). This outcome is summarized by Polkinghorne (quoted in Cresswell, 1998: 177) as follows:

> Produce a research report that gives an accurate, clear, and articulate description of an experience. The reader of the report should come away with the feeling that "I understand better what it is like for someone to experience that".

Sample description

Twenty-one (21) caregivers were interviewed for the study. Twelve of the participants were identified within the Maluti HSA and nine from the Teyateyaneng HSA. They resided in the peri-urban areas of Teyateyaneng town, the administrative town of the Berea District, and the rural villages of the district.

Socioeconomic characteristics of the caregivers and caregiving households

Households were reconfigured temporally and spatially for purposes of caregiving. Some of the participants were not ordinarily members of the same households as the patients prior to the onset of illness. They co-resided with the patients in order to execute care. In other cases, the caregivers and patients normally belonged to the same households. The socioeconomic characteristics reported were those of the households (caregiver's or care-recipient) which were responsible for providing labour and financial resources used to provide medical and physical care for the sick person.

The demographic configurations of most households showed one of the significant impacts of HIV and AIDS epidemic on family structure – its fragmentation. Widowhood, siblings-only constituted families, elderly-headed households, extended families which included orphans and orphans who were growing up in foster families were some of the reported features. Some of these constitutions did not only render the households economically poor they also restricted the households in terms of the availability of suitable carers.

Most of the caregiving households were economically poor and the members had low educational attainment. None of the caregivers had educational qualifications beyond the secondary school certificate and some children of school-going age withdrew from school because the families could not afford school fees. This was the case in situations where the children could not benefit from the universal free primary education policy because they were already in higher classes. The households depended on subsistence agriculture for a livelihood but also received welfare support in the form of food parcels from government and non-governmental agencies as part of the HIV and AIDS intervention. However, such support ceased immediately when the patients died, thus exposing households to vulnerability before they recovered income lost during caregiving. Some of the household members of working age were not employed while others depended on irregular economic activities such as home-brewing and casual jobs. A few caregivers also mentioned menial jobs such as domestic work for middle income families. Only five of the households had access to regular income from the transport, handicrafts, manufacturing, public service sectors and domestic work in the Republic of South Africa.

Generally, the studied households belonged to the low socioeconomic class and they did not have the necessary amenities and resources. In some cases, housing, sanitation and water for domestic use were inadequate. Some caregivers referred to lack of privacy and exposure of children to the patients' suffering due to insufficient living space which family members shared and divided between care and other family activities. Water was a vital resource needed for bathing the patients and washing their clothes, especially their bedclothes when they had diarrhoea. Most caregivers depended on water from community sources such as stand-pipes and natural springs. They reported frequent water shortages due to imposed communal water restrictions which affected their care work but also observed that while rainwater was useful, rain also added challenges because the patients' clothes took long to dry. Some of the very poor caregivers reported lack of access to safe water because they could not afford user fees. Most households owned appropriate rural sanitation facilities such as ventilated pit latrines.

Table 1 depicts three categories of the caregivers according to their caregiving status. Nine (9) of the participants were ex-caregivers while four (4) of the twelve (12) who were active caregivers when fieldwork commenced became bereaved during data collection. They were therefore interviewed while caregiving was ongoing and after the death of the patient.

Table 1 Caregivers according to their caregiving status

Health Service Area	On-going	Ongoing but later exited (O/E)*	Had exited already
Maluti SDA Hospital	7	1	5
Berea Govt Hospital	5	3	4
Total	12	4	9

O/E means that caregiving was on-going when first contacted, but ended during fieldwork due to the death of a patient*

Caregivers' age

The interviewed caregivers were aged between 23 and 85 years. Although there were more caregivers aged below sixty years, there were also eight elderly caregivers (aged 60 – 85) who cared for patients who were younger. Intergenerational caregiving was another aspect of the caregiving relationships across the entire age spectrum; adult children provided care for their parents while the elderly cared for their adult children and grandchildren. Intra-generational caregiving relationships involved siblings and in-laws.

Caregivers' gender

Sixteen of the caregivers were female and five were male.

Table 2 Caregivers according to health service area, sex and caregiving status

Health Service Area (HSA)	Male	Female	Total
Maluti SDA Hospital	2	10	12
Berea Government Hospital	3	6	9

Total	**5**	**16**	**21**

The gender representation reflected the findings of both mainstream sociology and feminist research on family caregiving. Studies show that caregiving, is predominantly a women's responsibility (Graham, 1983; Berg-Weger, Rubio and Tebb, 2001; Yamamoto and Wallhagen, 1997). It is argued that in many Southern African countries, the HIV and AIDS epidemic and the shift from hospital to home-based care perpetuates this situation (Mvududu and McFadden, 2001). Tolliver (2001:145) indicates that although AIDS threatens the whole family system, female caregivers in the African-American communities are 'the hidden victim of AIDS'. In Lesotho, women are the key decision-makers in family health related matters that affect themselves and their children (Romero-Daza, 1994: 194) but their ability to influence male adults regarding their health behaviour may be limited by gender relations within the family.

Gender structure of care relationships

There was cross-gender caregiving which involved males who provided care for female care-recipients. Their care-recipients were either spouses or daughters. Some female caregivers too provided care for male patients in non-spousal and non-parental relationships. Altogether, there were eight participants (six female and two male) who provided care for patients of opposite sex (Table 3).

Table 3 Caregiving gender structure

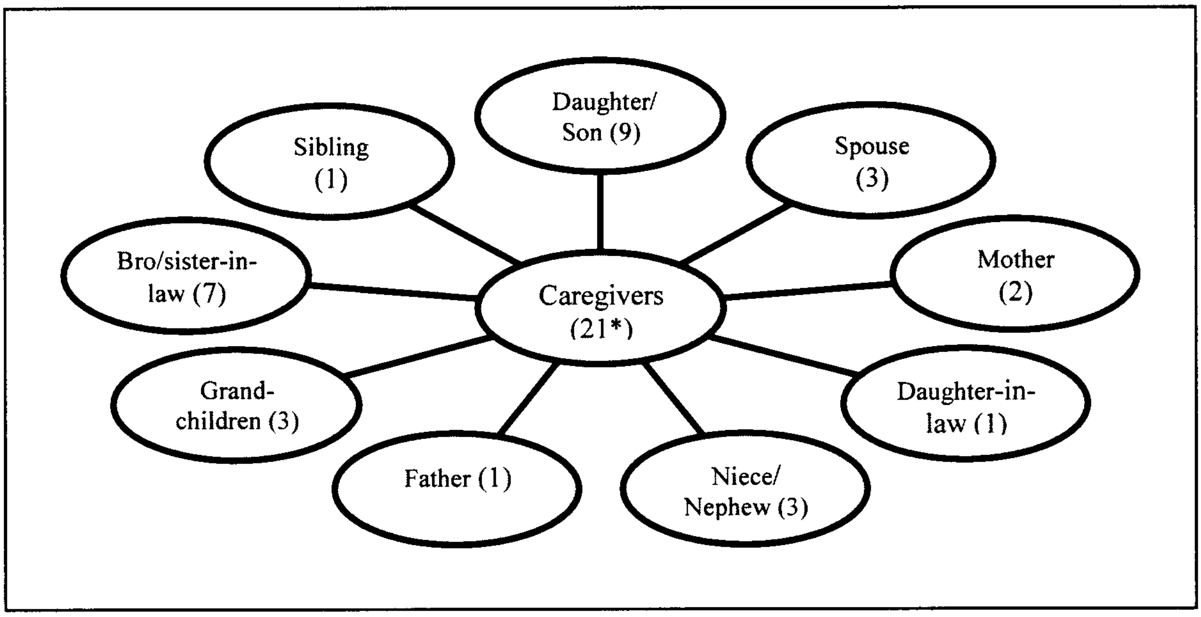
Caregiver-care-recipient gender	Berea HSA	Maluti HSA	Total**
Female-female (Ff)	5	7	12
Female-male (Fm)	1	5	6
Male-male (Mm)	3	1	4
Male-female (Mf)	2	2	4

***The total exceeds 21 because some were serial caregivers or provided care to multiple recipients concurrently*

Relationships between the caregivers and care-recipients

All the caregiver-care-recipients relationships among the study subjects conformed to the traditional definition of family whereby blood and marriage were the main criteria for defining who qualified as family. Immediate family relationships included spousal, siblings and parent-child relations but some of the caregivers provided care to their close next of kin such as grandchildren, nephews and nieces. Caregivers included spouses, mothers, fathers, daughters, siblings, sons, grandmothers, mothers-in-law, sisters-in-law, uncles and aunts. Some caregivers provided care for their married daughters and siblings even though customarily, matrimonial kin were expected to perform the role. Figure 1 shows a web of family relationships among the studied caregivers and the care-recipients.

Figure 1 Types of relationships between caregivers and care- recipients



*** The number of care-recipients does not tally with that of caregivers because of serial caregiving*

To a large extent these caregiving relationships resemble the African traditional kinship structure in which both the nuclear and extended family relationships persist. However, the caregivers' experiences inform us about the processes which led to the availability of caregivers.

Duration and incidence of caregiving

Although some participants reported caregiving which extended beyond one year, most caregivers provided care for more than six months but less than twelve months. The duration of caregiving was the time the caregivers spent as carers, and did not necessarily imply the duration of illness as these two tended to vary. Also, the caregivers' descriptions of the duration as expressed in terms of months or years of caregiving differed from their subjective verbalisation of the time spent providing care. Most caregivers tended to prefix their responses to the question on duration with *'it has been for a very long time'* or *'we come from far with X'* but these 'lengths' varied and were framed according to their experiences about caregiving, the intensity of the symptoms and care work and the outcomes of their actions. These descriptions were also linked to the metaphors of caregiving as a 'journey' and as a 'battle'. For example, providing care for different patients simultaneously and dealing with complex symptoms were subjectively described as lengthy.

Most of the study subjects provided care for one family member. However, five caregivers provided care for more than one patient in a sequence while four of the participants provided care for more than one family member simultaneously. They included a father who cared for his teenage children and spouse, a mother for two daughters and a grandmother who cared for two grandchildren. Their significant experiences related to specific individuals but they also compared their experiences across the various situations. Some of the younger caregivers had seen other members of their households including the current care-recipients providing care for family members who died. Some participants witnessed caregiving which ended in bereavement. Other caregivers could link the illness in their families to the HIV/AIDS disease. There were also caregivers who indicated that frequent illness and death in their families attracted stigma from some of the community members who referred to them as "AIDS families". So, AIDS formed part of the caregiving context. Bereavement occurred between December 2002 and January 2004.

Caregivers' awareness about HIV and AIDS status of the care-recipients

Most caregivers reported that they accompanied the care-recipients when the latter sought biomedical health services obtainable at health centres that included the two hospitals. However, some did not specify the medical condition that was diagnosed. Instead, they reported myriad symptoms which patients had or the discomforts which they reported. Some suggested that it was difficult to stipulate any specific factor as a cause of illness because almost all the parts of the body were affected by pain. Invariably, the caregivers often criticised what they referred to as the "patient-doctor secret" since the advent of HIV and AIDS. There were two broad categories of caregivers: those who volunteered information about their perceptions concerning the link between the symptoms and AIDS but did not have medical evidence from the doctors or the care-recipients. Their suspicion was based on the symptoms and gossip. Another category consisted of those who explicitly associated the illness with HIV and AIDS but disclosed such information in different ways: for some it was easy to acknowledge HIV and AIDS from the beginning but others took some time before they could disclose it. In some cases it took more than one interview meeting for the caregivers to develop trust, especially in cases where caregiving was ongoing. There were those who knew about the HIV and AIDS diagnosis early in their caregiving career because they were involved from the onset of the illness. Such caregivers actively searched for diagnosis and were informed by the healthcare workers. Some only discovered after the death of the care-recipients and there were none who were informed by the care-recipients.

Shortcomings and possible sources of bias

I identified the study participants with the assistance of the hospital personnel because it would otherwise be difficult to reach the caregivers without involving the health care institutions which conducted the clinical diagnosis and were gatekeepers in this research area. The selection of possible participants depended solely on the health workers in the hospitals; they did it on the basis of their records (which were effectively confidential) and the willingness of the caregiver and the patients to participate in the study. The selection bias that could have been introduced by reliance on health workers is that the participants could be those who were positively viewed and preferred by the health care workers for different reasons.

Nevertheless the experiences gathered did not suggest serious shortcomings in terms of response patterns to various issues, except that the participants tended to be mainly from the low socioeconomic class. While the descriptions are biased in this way and perhaps have a potential to stigmatize the poor, it should be seen as an inadvertent outcome of a sampling procedure over which the researcher had limited control. Viewed positively, the study may be seen as having reached the sector of society that has to adapt to the presence of HIV and AIDS in the family through uniquely difficult ways due to poverty.

Considering that the caregivers were interviewed about their *significant* experiences, the problem of memory lapse which may be a threat to reliability especially in survey interviewing was minimised in their descriptions. This is because as Wagner (1983) asserts memory provides access to experience, and "[H]uman beings have the capacity to remember what has passed away in their experiences, beginning with what has occurred a short span ago, and reaching back into more remote times of their lives...every experience leaves its traces in consciousness" (Wagner, 1983: 34). It is usually possible to recall and be consciously aware of what was once imprinted on one's mind as a significant experience.

Ethical Issues

Although I do not think that confidentiality with HIV positive status benefits families, I had to consider the possible repercussions of betraying the trust which the health care providers had when they included me in the 'shared confidentiality' among professionals for the purpose of contributing knowledge in this area. They were interested in how I would pursue the study without suggesting that the illness was HIV and AIDS-related as they had to respect the promised confidentiality and were concerned that such revelation could affect caregiving negatively. Qualitative researchers are divided on the issues concerning covert and overt research. There are those who would argue that failure to be completely open with the study participants about HIV and AIDS caregiving as the specific focus of the study was deceitful. A classic study that adopted a covert approach and raised ethical questions was Laud Humphreys' doctoral thesis on homosexual practices in public rest-rooms in the 1970s (May, 1993; Hornsby-Smith, 1993). Degrees of covertness differ and as Fielding (1993: 158) argues, "a covert approach is controversial, but may be acceptable in sociology". I followed the approach which other qualitative researchers refer to as 'situation ethics' (Punch, 1998; Fielding, 1993). They argue that since general principles collapse when confronted with dilemmas researchers should deal with ethical problems *situationally or as they arise.* It is generally acceptable that researching closed situations is not easy and HIV and AIDS is one such situation.

Arguably, scientific interests should not undermine the privacy of individuals but where such a pursuit is made in the interest of the general human race and advancement of knowledge, sociological studies of the nature described above are considered justifiable. The current 'over-protection' of the rights of the people affected by HIV and AIDS and the social taboo which emanated from stigma or denial and was realized through confidentiality and glossing-over HIV and AIDS status with chronic illness, as if there were no major variations, render HIV and AIDS issues at individual level highly secretive. It may be argued that the situation makes those who are affected by the epidemic invisible and that it is the responsibility of social researchers to find ways of illuminating this aspect of life in society. This is because it may also be possible that confidentiality will inadvertently lead to the exclusion of the people affected by AIDS through caregiving. The path was therefore chosen in order to avoid the restrictions that may hinder access to this section of the population and to advance knowledge about how the people who became responsible for the care of the patients who were not admitted to hospitals because of the nature of their illness grappled with the responsibility. The *epoché* provided the opportunity to study the caregiving situations while observing shared confidentiality. Considerable caution was taken to ensure that this study would not harm the caregivers, the patients and their families by unintentionally revealing the information about the patients' diagnosis or even my thoughts about the mentioned symptoms. It is therefore anticipated that the study has not "spoiled the field" for future research. This was partly indicated by the harmonious exit I made at the end of fieldwork and the ability to make follow-up visits whenever it was necessary.

Definition of key terms

Experience: This term is core to phenomenological research. It refers to a combination of the expectations of the caregivers and the actual constitution of the objects about which they are conscious – what they think about, see, perceive, feel and judge on the basis of their own understandings as derived from memory, image and meaning. They can be pleasant or poignant.

Care: It entails the social practices through which the members of society ensure that the needs of the ill persons are met. Families, medical and health care services are important components of these arrangements and there are structures through which the needs are met as well as the values which guide the delivery of such assistance.

Caregiving: It includes the various activities which the study subjects carry out daily to meet the needs of the cared-for at home and in relation to the hospitals. It happens when the study subjects recognise the declined capacity of the cared-for to meet their needs independently and consequently assume the responsibility to help. It entails ameliorating the physical and emotional pain of the cared-for while also attempting to reduce their personal distress. It is the subjects' "world of working" (Wagner, 1983).

Caregiver: A family member who assumes the responsibility to perform tasks for the chronically ill persons, mainly at home, and is in constant contact with the ill individual. It can be a male or female family member who is physically and emotionally present at the place where care takes place – the home and/or hospital.

Care-recipient: A patient with chronic illness who is unable to perform the activities of daily living on their own or pursue medical treatment without assistance. The term is used to distinguish between a patient in a professional care relationship and a sick person who receives care from a lay person within informal relationships. But patient and care-recipient is used interchangeably where this distinction is not vital.

Care context or environment: These are the circumstances that prevail in society and shape the ways care is practised and the experiences of the caregivers. They include the political/policy, medical and social factors that affect decisions about what care should entail, where it takes place and at what cost.

Demedicalisation of care: This practice is juxtaposed with the notion of medicalisation. It refers to a care policy which encourages society to pursue life and uphold values that discourage dependence on medicine. It is the view that medicine in not panacea and that some problems in society may be solved outside the realm of medical power. In the case of HIV and AIDS care the practice involves emphasising nutrition and deemphasising ARVs in prolonging life of the infected individuals.

Chapters Four, Five, Six and Seven below present the findings of the study. Chapter Eight draws the conclusions on the major findings of the study.

CHAPTER FOUR

DELAYED CAREGIVING AND THE CHALLENGES OF KNOWING DIAGNOSIS

When individuals fall ill, they typically inform their close family members and friends if these familiars cannot see the obvious signs of illness. The family members may respond to the illness even before the medical perspective on the condition is obtained. They become part of the help-seeking behaviour and attend, with the patients, the medical consultations through which they would know the details of the illness. In many African cultural contexts biomedicine has been practised without strict adherence to confidentiality. When biomedicine was introduced to the Basotho society in the nineteenth century, to a large extent, it adapted to the values pertaining to the family relationships as a framework for responses to illness. In this way, there was continuity with regard to the cultural norm of collective response to illness as emphasized by various writers on the continent. The advent of HIV and AIDS seems to have disturbed the harmony between biomedical and cultural practices profoundly. The health care professionals emphasise confidentiality in the medical care relationship and there is a tendency among PLWHA to keep HIV diagnosis a secret. Family caregivers encountered unique challenges when the responsibility of caring for the patients with AIDS-related illnesses was placed primarily within the home domain, yet they would not normally be informed candidly about the onset of illness or the underlying cause of the symptoms which were perplexing.

This chapter analyses the experiences of the family members about the process of initiating caregiving. The argument will be made that the manner in which the caregivers became involved in caregiving produced diverse caregiving experiences. These were influenced by the social and medical factors which influenced communication about the illness and diagnosis among the family members on the one hand, and between the health care personnel and the caregivers on the other. Firstly, it will be illustrated that the 'delay' and failure by the care-recipients to inform the caregivers about their illness produced poignant experiences at the early stage of caregiving and deprived the patients of the earliest care possible. The factors which led to late initiation of caregiving included the unusual behaviour of the ill individuals and other relatives, who did not communicate the illness until it was advanced, and the care-recipients who ignored the health or physical changes which the family members recognized as worrying. Multiple task performance and protracted family crises as a result of providing home-based care and bereavement also contributed to 'delayed care'. Secondly, to a large extent the caregivers considered knowing about the cause of the illness integral to their caregiving responsibilities. As a result, the degree to which the healthcare providers upheld confidentiality for HIV and AIDS diagnosis and how they communicated clinical outcomes influenced the caregivers' experiences with the process of obtaining diagnosis and their perceptions about the outcome.

'Delayed' caregiving

Patients and family members did not report illness

Many caregivers initiated caregiving long after the onset of illness because they were not aware, until late, that their relatives were ill, and their emotional experiences were the consequences of this late awareness. Since many caregivers did not live with the patients, they depended on the patients and other kin to inform them about the illness. The difference in time between the onset of illness and their initial awareness of the illness was indicated by the physical conditions of the patients when they eventually met them. Consequently, their experiences during the initiation of caregiving were as a result of the unpleasant observations they made about the patients' corporeality – the change which they observed through the symptoms, physical appearances and lost functionality. The situation produced poignant experiences during the initial encounters; mainly sympathy, fear, shock, anger and disappointment. This was because the patients were in distress due to the disease progression, suffering and inadequate care.

Most caregivers blamed the patients for concealing the illness and the other kin members who lived close to the patients for being unresponsive to the predicament of such patients. The patients were in a state in which they could not cope on their own or with the help that was available at the time. In some situations they were concerned that caregiving was done by unsuitable and incompetent individuals in terms of age and gender. But they were also disappointed by the patients' lack of trust in them; and choosing instead to suffer in silence while other relatives also withheld their caregiving.

Some caregivers criticized the patients for staying away from home though they were aware of their health condition. As a result they were worried that the patients could have died away from home. A relative who was surprised by the behaviour of the patient she did not expect to survive said:

> *... when she arrived here from [...] she could not walk and I asked her, what's happening and she just said she was sick, her feet ... I was shocked to see her in that way. She lived there and did not come home until she was brought by [...] because I think he also did not know what to do, she had so many problems already and that hurt me because she and me we never fought even once...The neighbours there hired a van to bring her home because I think all her money was finished, and now it was me and her for all these three months she spent here, but there was no way she would live... (Sister-in-law4)*

An uncle was informed by his nephew's friend that he was in hospital. The patient stopped visiting home and stayed in an urban area where he worked after being retrenched from the mines in the RSA. The caregiver was annoyed by the patient's behaviour because he did not understand why he cut ties with the family and dealt with the illness alone. He said:

> *I was shocked when we arrived at the hospital and found my child lying there, he was finished. I could not believe my eyes, that it was him; he was small and he looked older, he is much better now. It is true that I am not yet completely happy with his health but at that time he scared us... (Uncle2).*

But some of the patients ignored the early signs of illness. A mother of an adult migrant worker noticed that her daughter was not well when she was at home during holidays. She observed several conditions such as rapid weight loss and coughing and the patient also complained about chest pains and genito-urinary problems. But the care-recipient postponed seeking medical care. She expressed annoyance about the patient's dishonesty regarding her deteriorating health condition but also because the younger sibling had to provide care in the meantime. She also panicked when she realised that her daughter could die away from home and the family would incur costs to transport her body home. She said:

> *You will realize that her condition was serious because...she stayed there for two months not working... until she had to lie down. When she phoned to my neighbour's house she told me she still could not go to work. I asked her, 'what is the use...?' she told me that she had been to the clinic and they were treating her; may be she would be better...I could sense that she was very weak and as we were talking she choked, coughed, coughed until we terminated the call. That phone call, I cannot forget it... At that moment I wished Orkney was that side of the mountain... M said she could still make porridge for herself but I felt that she was not telling me the truth... I was so worried thereafter...I did not sleep, the whole night I was wondering what could have happened after that choking and coughing. In my imagination I saw her dead... I even dreamt of her dead and we did not have money to get her corpse home... I was very terrified when I saw her condition because even*

> *to me it is still like I am dreaming to see her alive. This child had lost life completely; even the people who saw her declared her dead… (Mother3)*

Other relatives, especially the in-laws who lived close to the patients were also held responsible for keeping the patients' parents and siblings in the dark about the illness while also withholding care. A caregiver of a patient who was staying with relatives who did not bother about her deteriorating health and sent her home when she was very ill, was shocked that they only paid her taxi fare and did not accompany her home despite her severe illness and said:

> *…this girl left home…and she was still well. She stayed there … and after three months she came back, very ill. When she arrived here I was shocked to see her in that condition; she was critically ill; when you saw her you would think that she had stayed in hospital for three months. She was very weak; she couldn't even bear the weight of a blanket on her shoulders (Aunt)*

An elderly mother blamed the patient's in-laws for neglect. She was distressed when she found that a teenage grandson was providing care for his severely ill mother. She was disturbed by the message but was more distressed when she saw her daughter's care situation. As a result she instantly decided to stay with the patient and assisted the children who were providing care for a bedridden parent. She said:

> *…from the beginning when I got the message that she was ill, I could sense the seriousness of her illness even before I saw her... Her in-laws did not give a damn… I did not go because […] in-laws had informed or even requested me to help her… and there was no adult caring for her. She is my child and she did not have someone nursing her… I found that she was being helped by her son, that boy who you saw! But she was already very weak. I realized that there was no way I would go back home, old as I am, and leave her in that condition… Her in-laws knew very well that she was ill… and they could not even assist me by simply informing me that my child was ill… I was touched when I found her at her home because I could see that she was very ill but trying hard to be strong… She was already lying down... I was shocked because I saw something I did not expect to see with someone who you are told for the first time that she was ill. (Mother1)*

Similarly, a caregiver who responded spontaneously and abandoned her work to provide care felt that her sister's in-laws neglected the patient and failed to inform her parents about the illness despite her devoted caregiving for their son who died from AIDS-related illness. She was hurt because the family had to depend on strangers who sympathized with the patient who lived alone in a rented room. She said:

> *She was given this room (by her matrimonial uncle) but no one came to live with her even though she was very ill until my mother and I came here to help her and she was very ill. She was admitted…my mother had to go home to check other family members and her fields because it was time to weed and she had to go because there was no way we would survive. When I saw her I then decided that I was quitting my job… I was working as a domestic helper. I just left like that and*

> *stayed here to help her… We got a note that was given to a taxi driver, that she was very ill and when I came here with my mother, we found her almost dying and we took her to the hospital… After the death of her husband she was already very ill but her mother-in-law abandoned her leaving her very ill... After his death she made it clear that she had nothing to do with her (Sibling)*

Another mother indicated that she became a caregiver of her married daughter because her in-laws neglected her. She was displeased because they did not help her child when she was hospitalized though they knew that it was imperative for family members to bathe their sick relatives at the hospital. Her view was that the in-laws were paying attention to their own son who was concurrently ill and she accused them of blaming her child for bringing the disease to the family. She argued that:

> *It is true that she was married but I realised that her in-laws were not bothered by her illness. I then decided that I should take up the responsibility. When she was at the hospital they neglected her; they did not bother to go to the hospital to bathe her, and I had to go there myself and bathe her. I brought her clothes so that she could wear fresh clothes at the hospital. We tried to involve them while she was there but they did not. I then decided that I should go there (to her house) after she was discharged from the hospital following the birth of her child and I nursed her (Mother2).*

The patients did not personally inform the caregivers about their illness; other individuals intervened by communicating what was at the time a critical situation. A young married daughter cited two occasions, which provided the patient the opportunity to inform her about the illness. She was shocked and angry when she had to report home urgently. She was annoyed because she believed her mother premeditated to keep the illness a secret even though they had a close relationship. She could not understand why her paternal relatives would not care for her mother. She was also anxious because she realised immediately that this could be a precursor to tragedy since her father had recently died from an undisclosed illness. She said she expected her mother to be open with her:

> *I came here during my father's funeral and I returned home. I thought that my mother was somehow unusual but I just thought it was because of pregnancy and my father's death… She did not say she felt ill or anything and being first born and a girl we were very close… I still don't know what was happening because I had spoken with my mother…before I got the message that my mother was very ill… I got scared but I was also angry with my mother because I could not understand why she would not tell me when she was ill. I am not a child anymore… That night I did not sleep at all because when you talk to someone you can tell from their tone when something is serious...she said "[…] I think my sister is very ill. You should not panic though; God is great may be He will pardon us this time". May be, do you hear that my sister, that's what she said. "But you should make arrangements to come home soon". I got very depressed because the only ill person I had been worried about was the little baby…I am not a child anymore; I added 2 and 2… (Daughter)*

Although many caregivers attributed the gap between the onset of the illness and the time they were aware of the illness to the fact that they did not ordinarily reside with the patients, they also observed that the patients had long initiated seeking medical help from the hospitals, private doctors and herbalists. Others observed that some patients opted to deceive them about their health condition even though it was deteriorating; the patients did not ensure that the people who became their carers knew about the illness before it was severe.

The patients ignored and denied significant health changes

The caregivers observed physical changes which they perceived as signalling sickness but their relatives denied the significance of such or postponed to address them. Some of those who observed the onset of worrying symptoms alluded to the patients' disregarding the early warnings about the physical changes which they believed deserved medical attention. Others initially denied that anything was wrong with their health, or deliberately cut off the caregivers from their illness experiences thus making it impossible to inquire about what was happening.

A caregiver who was concerned about her husband's inexplicable weight loss said:

> *... I saw him losing weight very rapidly but he said he did not feel pain anywhere. I could not understand so I asked him again and again and later he said he felt pain around his kidneys' area, and pains in the chest (Spouse 1).*

Another spouse stated:

> *Last year ... he surprised me. He had not said anything at that time about not feeling well but I saw that he was taking some medicines; he had them for one month but I did not know what they were for. I did not ask him because I know him, I know when he does not want to be bothered...on some days he did not go to work and when I asked he said he was tired. I could not understand what was happening but to me it was something new; he had never done it before, but what could I do? But later I saw him losing weight and that's when our fights in the house began...I did not understand why he did not talk about it... (Spouse3)*

An elderly caregiver indicated that from the beginning her late grandson denied that he was ill. She forcibly directed him to go to the hospital even though she would deliberately not ask him about his medical reports because she suspected he was secretive about the illness. She said:

> *He had been on and off for some time, complaining about this and that… He was one of the handsome children I have in this family. I saw his features changing and I asked him if he was ill and he said no. Before long he was complaining that he felt tired. I could not understand why a boy of his age (27years) would feel tired, he was not even working … I could see he was suffering secretly... I thought he was hiding something, but what I don't know. I think a lesson will be learned in this house that people cannot hide forever. This is what I tell this one* (pointing angrily at his other grandson who lay down wearily on the bed behind the door. He was very ill and only spoke softly when I greeted)…*I said to this one, ask your brother maybe he has a problem which he is not free to tell me...you know how young people think. But they were not good friends so it was not useful.* (Referring to the current patient again) *I tell him: talk to me; but all I hear are stories that don't make sense (Grandmother)*

While she was nursing her late grandson, his brother's family was befallen by a crisis; all the members of his family became ill and she had to care for all of them simultaneously. She said:

> *They were all ill in his house – his wife, his baby…His baby fell ill first, then his wife so when I had gone to see his wife after being in hospital with a child, I realised that although he did not want to show, he was not himself. I could understand that his family were ill so what could I expect. A few weeks later his wife was taken to hospital and while she was there their child died. I was disturbed but I prayed to my God. This woman came home and on the day of the funeral, this 'boy' was in his house very ill. He could not attend the funeral of his child; this child was ill, he is better now. Thereafter, both of them were very ill… The problem is that they don't talk… (Grandmother)*

The caregiver preoccupied

It was common to consider retrospectively that what could have been early signs of sickness were mistaken for emotional distress. If caregiving followed bereavement, the caregivers were likely to be unaware of the physical changes that would ordinarily cause immediate concern but also readily attributing the changes to depression. For example, shortly after his spouse's and child's death that died within the same week, a caregiver noticed that another family member was severely illness. He believed that the illness was triggered by giving birth. He had been preoccupied with the other two family members who were terminally ill and was oblivious of his daughter's illness which possibly began during pregnancy. He stated:

> *Her brother passed away but at this time her baby was not yet born, she was still pregnant. Then her mother died too. After burying her mother then she went to the hospital to deliver. My daughter fell very ill after delivery, her baby died first; you see I had just buried her mother and brother now it was her… Then the baby died and my daughter remained behind but still very ill…She was intensively sick for one month, also complaining about chest and back pains. She coughed a lot and the way I see it, it was the same disease as her brother … (Father2)*

A mother, who provided care to two children simultaneously, indicated that her daughter, who was single and living with her, developed a minor condition which later surprised the family members because it failed to respond to treatment. It certainly appeared insignificant compared to the critical condition of the elder daughter who was married and staying with her husband but did not have a carer. Thereafter, her younger daughter began to lose weight rapidly even though she ate well. She observed:

> *She started with a finger, she developed a boil on her finger, and we took her to the hospital but it did not get better, but we continued to go because she was dressing the finger daily. 'After sometime, the boil on the finger began to heal but then she started saying that she felt pains in the chest']... (Mother2)*

Similarly, a caregiver who assumed the role after the death of two family members who had previously provided care became immensely involved in the caregiving of his nephew who was acutely ill from time to time. The two women who provided care before died and left him to assume the responsibility. Prior to this he was remotely aware of the patient's condition. He said:

> *It seems that from his birth he was already ill. From that very early stage he showed signs of ill-health. But since my parents were still alive they were the ones who were responsible for his care and they would take him to the hospital and many other doctors...After their death I left my job because there was no one (adult) staying at home, and there were many things to take care of ... I then realized that this boy was really ill. Now that I was at home I became aware that his health was not good (Uncle1)*

A father of a girl who was sickly but whose condition suddenly took a new turn said:

> *She fell ill in 2002...We left this girl to help her mother because at the hospital they said [her mother] needed someone to help her since she was very ill and could not do anything on her own; she needed someone to bathe her and so on... She then got infected by her mother. Her mother died in 2002 and since then she has never been well. After her mother's burial, I realized that K was very ill. It's true that she grew up a very weak child who was always ill but this was new – what we saw was new. After leaving her at TY to look after her mother she became sick but it took us time to realize that her health was declining. It took us time before we could realize even the cause of her illness. But I'm telling you, [...] hospital brought her life back given the way she was when she was first admitted (Father1)*

In situations where the participants were involved in serial caregiving or provided care to more than one patient simultaneously, it was possible to overlook a patient's situation because they were preoccupied with caregiving responsibilities for other family members who were seriously ill. The new complaints appeared insignificant compared to what the caregivers would be experiencing with the other care-recipients. This could also be compounded by other family members who were reluctant to provide care. Some caregivers believed that younger people did not tolerate caregiving because it tethered them.

The caregivers did not perceive the symptoms as significant

Patients rarely informed the family members including spouses and parents about feeling sick. However, a few caregivers who were informed about the sickness before it became severe tended to underestimate its impending seriousness. The family members usually took cue from the sufferer about the seriousness of the symptoms unless their effects were visible and constraining. Sometimes the felt sickness did not interfere with daily activities or the sufferer did not express urgency about the felt discomfort.

A caregiver indicated that a patient returned home complaining of pains in different places. Two months later his symptoms intensified and he had to be taken to the hospital. He was shocked by the sudden turn from a condition which he had initially perceived as negligible to one which later threatened the young man's ability to walk, and said:

> *He started complaining about feeling sick in October last year. He had been at Maseru for about three months working there...in a security company. When he returned in the 4th month he came here and told me that he had chest pains and he felt cold in his feet and they were aching too. He could not return to work but he could still leave this house, go to town and come back. But later in December he became very ill and I took him to the dispensary (Father3)*

Another caregiver who was also unsuspicious about the symptoms at the beginning was an ex-carer who was suffering from a neurological condition (minor stroke) which she attributed to the stress that she endured while she was providing care for four kin members - two couples who all died and left her with nine orphans. In her account on one of the four care-recipients, who she considered as a 'friend', she regretted that she underrated the symptoms when they first appeared. She only became concerned when the care-recipient began to cough persistently. Although it was almost two years since she provided care she seemed distressed emotionally but insisted that she needed to talk about her experiences. She said:

> *[She] complained about back and chest pains for some time. But she could still perform many duties (in the family)... Immediately after completing [work in the fields] her condition became worse....I insisted until she went to hospital. I did not like it because she had started coughing very thick*

> *brownish sputum and when she coughed she would hold her chest tight because she said it felt as if there were wounds inside (Sister-in-law2)*

The experiences suggest that caregiving was initiated at different stages of the illness trajectory but in many cases it was delayed and only initiated later when symptoms were advanced. This was mainly because the opportunity to notice the onset of illness differed according to various circumstances of the caregivers and care-recipients. Whether the patients and the caregivers lived close to one another played an important role because the caregivers who did not normally live with the patients depended on them and other family members to communicate the illness. Many caregivers did not learn about the illness situations from the sick individuals. The caregivers who found late that the patients were ill had poignant experiences because the patients were severely ill with varying degrees of disability, while the form of care they were receiving was inadequate. Sometimes the patients did not involve the caregivers in the early stages of their illness experience even in situations where they lived together – a situation which should ordinarily provide the opportunity to discuss the illness. For example, this occurred with spouses, and between children and parents or a parent-figure such as a grandmother. The physical changes which occurred early did not immediately attract attention because they appeared insignificant or the family was undergoing major crises which rendered the complaints trivial. The response to the care needs of the patients was inhibited by poor sharing of the information regarding the illness experience in the family. This was also a common feature of the caregivers' experiences regarding information on diagnosis.

Diagnosis: searching, the need to know, doubt and secrecy

Care involves the recognition that the ill individual may not meet their needs independently. Since such needs are defined partly by the illness and partly by the medical categorisation of the symptoms through diagnosis, information is usually sought and shared by those who are involved in the process of care. In chronic illness, the patient may not be absolved from contributing to the management of the illness. Since in most situations caregiving occurs when the illness has evolved to levels which warrant help by others, the patients initially manage the illness with minimum involvement of others including the family members though sharing of information among close kin is a norm. The initial steps of seeking outside help usually lead to the doctor-patient relationship through which diagnosis is made and treatment initiated and the family members may become involved.

Information concerning clinical diagnosis was considered crucial in caregiving and attempts to obtain it were made. In most cases, the caregivers depended on the care-recipients and the healthcare providers for such information because treatment had already been initiated. But some of the caregivers consciously pursued diagnosis because the available explanations were inadequate. It was necessary to establish the cause of the illness which was life-threatening and sometimes puzzling too.

The need to know what one is dealing with

The caregivers pursued diagnosis because they needed to know what they were dealing with and considered it crucial for practical, existential and emotional reasons. But the perceptions of the caregivers about the process of obtaining clinical diagnosis and the information provided by the patients and the healthcare providers depended on their own assessment of such information relative to their observations but they were consistently preoccupied with the search for medical diagnosis. The difference between knowing and not knowing were expressed by the participants who had varying degrees of the information, but the experiences of those who progressed from not knowing to being informed convincingly demonstrated the advantages of the latter situation.

> *Since he started taking the medication which he started in 2000 after he was tested HIV positive he has stabilized a little, there are no frequent episodes even though those that have occasionally occurred still frighten us but at least we now know what we are dealing with and every time we notice something that bothers us we don't waste time, we take him to the hospital (Uncle1)*

Similarly, those who knew about the HIV and AIDS diagnosis thought that they were fortunate while the medical staff member who revealed the HIV diagnosis was viewed as bold and helpful. They had anecdotes of elderly individuals who provided care without knowing. They handled the body fluids of the patients without precautions (*they were handling without discrimination)* and some died from the 'AIDS' disease. One said:

> *We went and we were able to complete the necessary procedures. After doing blood tests the counsellor explained to me, she told me: your patient has a problem. I did not understand so I asked*

> *her, what kind of a problem? She said she has this 'infection disease', meaning HIV/AIDS... (Aunt)*

A widower who had doubts until his daughter died explained that his attempts to seek clarification about the symptoms were trivialized by a healthcare provider, thus introducing feelings of helplessness while his thoughts continued to be preoccupied by AIDS. He stated:

> *But I was suspicious, but I was helpless with my suspicions...because I was a man and I needed a woman to discuss this suspicion with me. At some stage I was thinking of taking her to the hospital to discuss my suspicions with the doctors, I was in a dilemma because you see the medical doctors cause troubles for us... This girl I was suspicious that she could be having gonorrhoea... it was the same disease as her brother who had died. I think she had AIDS... That was just my suspicion but there is no doctor that confirmed my suspicions. I saw symptoms which made me suspicious but being a child and a girl for that matter I think she found it difficult to tell me. You see doctors never explained, they won't say a thing even when they see something. What could I do...? Well, my requests were all in vain. I even asked the AIDS counsellor herself, saying could you please tell me what is wrong with this child, and she simply told me that there was no 'bad sickness' that she had but she thought she should tell me herself. I don't know but I just thought that she was referring to AIDS. I don't think there is any other bad disease that people know these days. Isn't it we don't have lepers anymore. So when people say bad disease they mean AIDS (Father2)*

A caregiver who doubted the initial information regarding diagnosis appreciated the decision of the doctor to inform the family that the patient had HIV and AIDS even though she did not see him testing the patient and it was too late and the disease had progressed. The patient consulted the hospital and private doctors in the nearby town but complicated the care situation by ensuring that his diagnosis remained unknown to the family members. By disguising himself and using different names when he consulted doctors, he claimed he had tuberculosis yet he was not on a TB treatment, and failed to talk about the HIV and AIDS despite the caregiver's effort to help him disclose. Expressing gratitude and how she experienced the disclosure of diagnosis after long periods of doubt, she said:

> *...he became severely ill, this time he could not go alone so I took him to the hospital but the doctor said he could not see what his problem was. I could not understand how a disease would hide when someone was so obviously ill. But there was this one doctor who was bold and he just said it is AIDS and I still thank him... That doctor said something which surprised me: he said are you still so-and-so's boyfriend? He said yes. The doctor said, now I understand because that girl is also very ill, she needs to be checked too. You have HIV/AIDS! You know what, I thought the doctor knew that he had long been checked and that it was just a way of letting us know because his father and I were there and I was wondering what kind of disease was eating this child away. His booklet had gone missing and when we looked for his booklet that day we could not find it and he was very*

> *ill, and I did not like it that doctors were made to scratch their heads about someone who was not seeing the doctor for the first time… (Grandmother)*

Another caregiver thought that the previous caregiver, who had died from AIDS-related illness, did not probe enough despite the frequent illness episodes the care-recipient experienced. His consciousness about the illness was raised when he assumed the caregiving role. He reviewed the circumstances around the illness, in the light of the information he obtained from participating in the AIDS awareness workshops at the hospital. He said:

> *Every week there would be an episode…After some time I decided that I should find the root cause of his poor health. I pursued this with the hospital staff and asked them to assist me because I could not understand what was happening with this person. I asked them to do proper examinations and tests so that I could know exactly what I'm dealing with because I was wondering what is wrong with him. They examined him and they found out that he was HIV positive... (Uncle1)*

Another caregiver sought hospital care to obtain an explanation for the bodily pains that his son experienced. He wanted the patient to be hospitalised so that the doctors could observe him closely and detect his disease. He was concerned that during the first medical consultation he could neither obtain a diagnosis nor admission. He was depressed when a doctor could not provide an explicit diagnosis despite the patient being in severe pain. Subsequently, he demanded a comprehensive examination which led to a diagnosis which he found unconvincing because it did not fit the patient's biography, besides his condition did not improve. He stated:

> *I wanted them to get him into hospital so that they could see what was causing him the pains... I took him to the hospital again and they admitted him. This time they said he had accumulated a lot of water in his lungs. They drained the water. He spent three to four days at hospital…. I found out when I got there visiting him that he was still in pain but he told me he felt better. And I felt encouraged. When they took him for x-ray they said that he has TB. I was surprised to have him diagnosed of TB because my child has never been involved in a job that could cause him TB… (Father3)*

When the caregivers were distressed by the symptoms their eagerness to understand the cause of the recurring illness increased. Their expectation was that medical procedures would provide precise diagnosis by going beyond the observed symptoms. A mother said:

> *This thing had started at the clinic here when we had gone so that we could be referred to the hospital. It was said again at X hospital, that's why I did not want to take her there again… the patient said to me: 'but mother you heard what the doctor said when looking into my eyes? …When he opened my eyes he said, these eyes show that there is no life in me. I think he thought that I could not hear him, but I did and I think he is right' I did not know what to say because indeed the doctor had repeatedly said so (Mother2)*

An elderly caregiver who became involved while the patient was already severely ill desperately wanted the patient to consult a doctor so that she could be advised on how to assist the patient but also to know the cause of so much suffering which was 'destroying her body'. She was concerned about the uncertainty among family members regarding the illness and the gossip that she suffered from AIDS. The patient had also recently suggested to her in a noncommittal manner that she 'probably had AIDS'; she dismissed this because she thought the patient was too ill to talk sensibly. But the caregiver believed that an HIV test would also stop the speculations around the illness. She said:

> *The problem is that we are just muddling; these kids don't know what is finishing their mother, I don't know what is finishing my child. All that I do is to attend to her when she points to the area that is painful or uncomfortable... We could as her caregivers want to know about her status and her doctors to know too so that they can care for her properly knowing what they are doing and why. That's what I am requesting. If there is nothing, then I will know that there is nothing... What I think is that she can be taken to hospital and be checked, given medication and come back home so that we continue to assist one another – the doctors and ourselves with caregiving. It will be different from what is happening now because at present we don't know what we are providing care for. We don't know what we are doing...And you know what I still believe I would feel better if I could know what the problem is. It would be better than what I feel now seeing this child's health destroyed by an unknown disease. I always wonder what this disease is which did not even become better when she took medicines and causes this child pain day and night. I feel that for some people it is as if she is dead already and that everything that is done is a waste of time. It is the attitude in this family; it is like she is already dead... (Mother1).*

The common view was that it was easy for lay people to connect the symptoms to AIDS. This awareness was made possible by the public health education through the hospitals and mass media. But it was difficult to obtain the information from the patients even though as they argued, the symptoms only revealed the underlying disease. For instance one interviewee said:

> *You see when they have it, it is a personal secret with the doctor what we only see are the symptoms because we have been educated about AIDS symptoms. When people have AIDS they don't agree that they have it or even mention that they have it. But the orphans are so many in this village. When it is TB we come to know and many who have TB get cured. There is secrecy around HIV/AIDS and when people have it they will mention all these other problems that they have to an extent of saying it is a finger or a thigh or just body aches but they never mention that they have this infection (Sister-in-law1)*

Despite the barriers to information pertaining to diagnosis, the caregivers enthusiastically pursued it because they needed to know the cause of the illness which puzzled them through symptoms and bodily effects. Illness was more puzzling when it did not seem to respond to the medical treatments which were known for efficacy. This created the suspicion that the diagnosis was not adeptly conducted. Subsequent to diagnosis and prescription, the expectation was to see improvements and finally cure.

HIV and AIDS: taboo in the families

The expressed suspicion that the illness could be linked to HIV and AIDS was a common theme but the subject was taboo within the affected families. The caregivers were concerned about upsetting the patients but also avoided possible criticism from other family members who would not approve of the illness being associated with AIDS. People could only think of HIV and AIDS but they would not mention it in the same way they could suggest a test for hypertension, and TB, which used to be stigmatised, was discussed openly.

A sibling said:

> *No way! I kept quiet. I realized that her husband's death had devastated her and I did not want to talk about such things with her, I was reluctant to talk about it. When she first realized that her husband had HIV/AIDS she became devastated, she lost it completely, so there was no use telling her what I think. I thought about it all this time because I wanted to say to her: "don't you think that even before you fall very ill, you should go to the hospital to deal with this suspicion?" because I could see that she was equally worried that she could be 'having it' but I did not have the courage to talk about it. (Sibling)*

Another caregiver was also conscious that the illness could be due to HIV and AIDS and suspected that the patient knew. She was adamant that she would not expose herself to infection and therefore avoided contact with the patient's body and body fluids. She said:

> *But the issue of testing could not be brought by me to the family; it would be very sensitive. It is different from when it could be brought by you… If it could be me, it would cause lots of conflicts in the family. You can see how different it is, she has found it easy to say it to you that she wishes she could test for HIV … but she wouldn't say to me, my sister, you know I think this and this about my illness. But if I could say, what do you think of these symptoms? Don't you think that you should go for a test, oh! it could be something, I'm telling you it would be terrible, it would cause such feud even her children would think bad of me for just suggesting that their mother could be needing to do an HIV test not saying I think she has it because we don't know and probably we will never know unless she has done a test. (Sister-in-law3)*

Another one said:

> *But somehow I saw some signs which made me suspicious. That is why I gave him the information booklet (on HIV/AIDS) hoping that he would get the message, I wanted us to talk about it but I did not know how… No way, everyone would think that I am a witch; they would call me a witch or anything bad. I gave him the book and I expected him to be responsible because he was not a child, he was already 27 years. Can you see he was a man already? But I now realized that I made him wild because it said to him that may be I can see something, and he wanted to prove that I was wrong… (Grandmother)*

Healthcare providers contributed to ambiguity and doubt

The caregivers also had the perception that the hospitals were not helpful in disentangling the mystery concerning the cause of illness since the healthcare workers would not communicate the diagnosis, or they provided ambiguous and inconsistent information. The caregivers insisted on HIV testing when they were anxious and the patients were increasingly losing functionality or were completely dependent on them for personal care. They were worried about infection because as the disease progressed, the suspicion that they could be dealing with HIV and AIDS was entrenched in their consciousness. But they were concerned that their intention to use gloves would offend the patients and family members who might be sensitive that the caregivers were influenced by gossip. In this way, medical opinion would justify the use of gloves because they were associated with AIDS.

A caregiver involved a health worker because she was convinced that her mother was ill from AIDS but did not feel free to discuss the subject, she said:

> *I was depressed when I approached the counselling nurse and she told me…that they don't take blood tests for patients who are too ill because the outcome might make them even more ill. (Daughter)*

Another caregiver who insisted that the patient knew the nature of her illness said this about both the care-recipient and doctors:

> *When she arrived here… she just said she was sick… She said her son took her to the hospital and that her problem was in the chest, but they did not admit her, so I got worried why they did not admit her…I could see that even her head was not working well but I didn't know and his son, well, he's a child so he would not know everything, but she knows…I wanted her to help me help her because she would be hurt if I just used them (gloves) when she did not say she has 'this problem' … And they did not say it (diagnosis) at the hospital but we could see but they won't tell you even if it is your child… (Sister-in-law4)*

One caregiver stated:

> *I took that girl to see many doctors…there was a doctor there by the name of Dr… He talked about the pain on the back and in the chest…The doctor did not say what the cause of the pains*

> *was…I took her to the hospital and they mentioned the same problem, the chest… The painful thing about the doctors in our hospitals is that they won't tell you the diagnosis. I told them, this child is mine and now that her mother is not here there is no one else to know her problems but me. If she has a certain disease, they should know that after I have buried her I must be able to register her death accordingly with the appropriate authorities, the chief's office for example, what do I say to them because they inquire about the disease that the deceased had? (Father2)*

In another situation, the caregiver consulted two hospitals but neither TB nor HIV was diagnosed; they were detected when the patient consulted the third hospital even though the latter was later revoked. He said:

> *Since she fell ill it has been me and her going up and down trying this and that to help this child. As I told you I don't have 'the other hand anymore'…I took her to TY hospital several times and it was not clear to the doctors what is happening and I paid for her medication there; they couldn't tell me. I then took her to the […] hospital and even there they could not diagnose this disease and I paid. Anyway I paid because all I wanted was her life and health (Father1)*

There were instances when diagnosis shifted from one disease to another, but such inconsistencies were experienced differently by the caregivers. The common consequence of shifting diagnosis was anger and doubt. It was puzzling, when such shifts did not translate into improved management of the symptoms. This was a common perception when the diagnosis was tuberculosis because it was expected to have a positive prognosis. For example, a caregiver's account of a patient who was devastated after she was informed about HIV/AIDS diagnosis, which was later annulled and replaced with T.B. He recalled:

> *When she came back she reported that a nurse said that she is suffering from AIDS…she said 'father they say I have HIV/AIDS'. When this child came here she was crying and very devastated. I felt disturbed too and I went with her to hear what was happening and to support her if it was true… I was confused but I decided I would go with her to the hospital in case she was mistaken. She was terrified. But then with God's mercy, when I went the results told us something different… the doctors sucked a fluid from her spine and told us that she has TB. Their tests did not report AIDS. She told me that she was not even examined then; the nurse just looked at her and said 'this one has AIDS'. I could see her lighten up because when she came with the news about AIDS she was really confused. When we went for the second time they did the test again and found that her TB had subsided. She was later called to the hospital to learn handicrafts –sewing but she is too ill. They were encouraged to stay preoccupied with something (Father1)*

She expressed indignation and cynicism about the practices of some doctors who she believed initially misconstrued the symptoms which she thought could have been managed better at the early stage. One caregiver found all the diagnoses made to be in contradiction with her knowledge about TB. As a trained village health worker she was conversant with the public health problems including TB and HIV and AIDS. She did not associate the patient's symptoms with stomach ulcers and expected the patient to be on a conventional TB treatment which she highly trusted. Doctors were blamed for disregarding the emotions of the caregivers as they dealt with the patients daily without the needed information on diagnosis. A caregiver said:

> *I was suspicious and I said to her, T's wife had ulcers but after going to the hospital and being hospitalized for the same length of time as you she has recovered, but you don't become better, you even complain about feet, you only become better when you are taking medication… Is this ulcer?'… Before long she fell ill again, and we took her to the hospital… When they diagnosed TB I told her, you are now cured. I was saying this because I knew for sure that this hospital is very good at treating TB. … I saw the sputum and said, no, no, I don't see how this could be ulcers, with this kind of sputum! I thought about TB but the doctors were saying ulcer…I ended up reading the Bible for her because that is what they told us to do when someone is weak…Who am I to question what doctors and nurses who have been trained for years say? ... I just watched because they have this thing that their illness is a secret between themselves and their doctors. I respect it completely but it is painful to us who turn around with someone day and night and you don't know what to do (Mother-in-law)*

Any diagnosis including tuberculosis was doubted if the symptoms did not conform to the lay perspectives but suggesting that the doctor could not detect the cause of illness was found dubious. A caregiver said:

> *I don't believe anyone who goes to the doctor and comes back to say a doctor cannot see what his problem is. What is that? Is there such a thing? Even with me, old as I am, when I am sick and tell the doctor my problem he is able to tell me that a certain part of my body is not working well, that my heart is pumping blood in a wrong way, so what is this thing that young people and their doctors want us to believe. I am not going to buy it from anyone…I saw some of the signs but I am not a doctor and I thought that when he came back from seeing a doctor he would say, grandmother this is what they said. When I suggested that he should go with his brother I was hoping that yes, they will come back with something different, because I did not want to buy the TB story (Grandmother).*

Ambiguous diagnosis while the symptoms persisted led to continued search. Another caregiver stated:

> *When I had taken him there they told us…that they could not detect what his illness was. The doctor was saying he cannot see his problem. I said I don't understand this. But they gave him some tablets and we came home... I returned him to the dispensary and requested the doctor to take him for x-ray because he was saying it was in the chest... At this time he could not do anything because he said his whole body was aching…. He was crying with pain (Father3)*

The caregivers had different experiences about the information on diagnosis. Sometimes the enigmatic symptoms were medically linked to a disease which they perceived as a plausible explanation, namely HIV and AIDS. For other caregivers, obtaining diagnosis was one of the factors which contributed to stress in caregiving because they failed to obtain the information about diagnosis yet they could not discard the thought that the one which was offered to them was dubious. Consequently, what was communicated as clinical diagnosis was usually received with doubt because the caregivers believed that the information was obscured by the secrecy between the doctors and the patients regarding HIV and AIDS. Some suspected that the patients deliberately kept the information from the family members, including the people who *cared about* them and wanted to assist them to share their burden, namely the caregivers. The patients avoided talking about HIV and AIDS and 'hid' this particular diagnosis. But, the suspicion that the patients could be ill from AIDS-related diseases was not equivalent to having medically supported information.

Discussion

This chapter analysed the experiences of home-based caregivers about the process of becoming a family caregiver for HIV and AIDS patients under home-based care. The two phases in this process namely, being aware of the illness and forming perception that the individuals needed care, and establishing the cause of the illness by pursuing diagnosis were intertwined and integral to caregiving. Aneshensel, Pearlin and Schuler's (1995) construct of "start of care" specifies detection of symptoms within the family setting and diagnosis of Alzheimer Disease as two stages that lead to initiating caregiving tasks. On both counts it became clear that the initiation of caregiving in this study entailed complex processes and that difficulties emerged from within the home and the medical spheres alike.

Central to the caregivers' experiences when they initiated care was the health condition of the care-recipients and were related to how soon they became aware of the illness. Of significance were their emotional experiences when they encountered the patients and observed that the illness had changed their physical appearance significantly. These physical appearances symbolised the patients' suffering and the symptoms confirmed that the illness could be insidious because even seemingly minor or common symptoms transformed the body and produced severe pain. Sociological analysis recognises that social interaction is mediated through human bodies (Goffman, 1963; Kelly and Field, 1996; Lock, 1993; Weinberg and Williams, 2005; Persson, 2004) and the way the caregivers consciously experienced the patients' bodies aroused unpleasant emotions such as sympathy, anxiety and anger. These experiences show that the caregivers phenomenologically experienced the illness of their family members but also, their emotional response and agency were critical in the initiation of care (Tronto, 1993; Fry, 1992; Kuhse, 1997). Emotions are linked ontologically to care in the private domain as they are seen as part of the embodiment of those who provide care, namely women (Graham, 1983) as well as an ingredient of the caregiving activities (Graham, 1983; Rudrappa, 2004; Thomas et al, 2002). Therefore, the response of the participants to the patients' circumstances was a result of their subjective evaluation of the illness and the objective conditions of the patients, especially lost functionality and physical pain. The essence of care as an emotional response to the limitations of others and providing or doing for them – caregiving – is elucidated by various writers (Noddings, 1984; Fry, 1992; Tronto, 1993; Bowden, 1997; Kuhse, 1997; Thomas, Morris and Harman, 2002) and the emphasis is on the inevitability of care in situations where it is not possible for individuals to function independently.

The initial unpleasant experiences were due to realising that they intervened late. Failure to inform the caregivers about the illness and misjudging the seriousness of the symptoms were responsible for 'delayed care'. 'Delay' is commonly used to describe the difference between the time when people who experience illness are aware of the symptoms and when they consult a doctor (Dracup, Moser, Eisenberg et al, 1995). But the term is used here to describe the timing of the caregivers' response to the illness relative to the onset of the symptoms. Therefore, it was central to explicating the caregivers' negative experiences at the beginning of caregiving.

The initiation of caregiving depended on the caregivers becoming aware that their relatives were in a situation where they could not meet their needs independently or that they did not have competent caregivers at the time. They responded because they realised that the patients were constrained by the illness. But, due to adult life responsibilities, especially work or marital roles, the patients and the caregivers did not usually reside together prior to the initiation of caregiving even though they were close kin. This aspect was indicated by their living rearrangements most of which were configured in response to illness – relocation of the patients or caregivers, and oscillating between the places of care and own home by some of the caregivers. These moves were made to adjust to the disruptions which were introduced by chronic illness (Bury, 1982, 1991). The caregivers depended on the ill person or a relative to communicate the need for care. Consequently, some held the patients responsible while others blamed the other kin for not informing them about the illness on time and/or for their indifference about the illness.

Irrespective of who was blamed for delayed initiation of caregiving, it was clear that there were irregularities in the way some patients and relatives responded to illness socially. The behaviour of the patients was inconsistent with the concept of illness behaviour. Mechanic (1992) assumes that individuals observe their bodies and form perception of the bodily changes in terms of their significance, and on the basis of that decide on the necessary treatment and how they use care provided through informal and formal arrangements. Usually the appraisal considers the intensity and nature of the symptoms in terms of their bodily consequences such as pain and debilitating effects. Family members are usually depicted as integral to the process of symptom evaluation even prior to consulting medical professionals and play an important role when illness is severe. This behaviour disadvantaged the patients because they were deprived of adequate care at home. They could not be in hospitals yet they did not have suitable or competent caregivers who helped them to maintain their dignity which was threatened as a result of inadequate care, another aspect of their self-image which the caregivers intended to rescue. Chochinov et al (2002) found that apart from fear for death, the terminally ill were worried about losing dignity and being abandoned. Clearly their illness condition had exceeded a stage whereby it could be said that they were "uncertain over what was 'normal' and whether the health changes required medical attention" – a common reason for delay in seeking medical help (Corner, Hopkinson and Roffe, 2006: 1384).

The experience of the early symptoms does not provide certainty about when severe illness will attack. Carricaburu and Pierret (1995) refer to being HIV-positive as "a situation at the risk of illness" (p.66) but not being chronically ill yet, because people living with HIV (PLWH) may be asymptomatic. This observation is interesting in that it recognizes the difference between disease as a medical attribute and illness as a sociological phenomenon and individual experience. However, in a health care environment which had not technologically and medically adapted to the requirements of monitoring the HIV virus in the body, such as that of Lesotho, the prelude to severe illness marked by the development of physical changes and symptoms would signal transitions in one's health conditions. Various writers (Fife, 2005; Liddell et al, 2005) refer to the intrinsically insidious nature of chronic diseases including AIDS which encroach and debilitate the body slowly while depleting its strength. This characteristic would not necessarily make the disease preferable; however, it would mean that if the obstacles to open communication were minimized, the caregivers would experience the initiation of caregiving in a less stressful way. But, since part of the response to diagnosis of a life-threatening illness could be denial (Fife, 1994) it was possible to fall ill unexpectedly and communicate own illness early enough.

Both the patients' and relatives' behaviour may also be explained in terms of stigma. The secrecy on the part of the patients in relation to the caregivers suggested that *felt* stigma more than *enacted* stigma (Scambler and Hopkins, 1986; Jacoby, 1994; Carricaburu and Pierret, 1995) influenced their decisions to conceal their illness. Possibly, in anticipation of stigma, loss of face and esteem in the eyes and minds of the family members the most reasonable strategy would be to keep the illness and disease a secret. The expectation that the HIV and AIDS-positive status would lead to rejection could be a sufficient modifier of behaviour (Link and Phelan, 2001). Jacoby (1994) found that epileptic patients concealed their condition and experienced psychosocial problems related to self image due to felt stigma and not so much the actual reactions of others. However, research on illness-related stigma indicates that when a family member is confronted by a stigmatising illness, the family responds as a unit and manages the stigma collectively. Neither the suspicion about HIV and AIDS nor diagnosis led to withholding of care among the studied caregivers. But, it has been considered typically different with HIV and AIDS. Negative attitudes such as unwillingness to associate with persons with AIDS are ubiquitous and are experienced from "sacred domains – family, medicine, and church" (Poindexter, 2005: 2). Although illness in general is heavily loaded with ideas about morality, some diseases are more predisposed to such negative judgement than others. Gwyn (2002: 109) argues, "HIV/AIDS can be used as a yardstick for the moral valency attached to other disease outbreaks". It was not surprising that some of the caregivers' experiences involved patients who did not have adequate care before they initiated caregiving. For example, the in-laws of some married female patients and other relatives were criticised for their unresponsiveness to the severe illness and care needs of the patients.

Culturally, married women belong to their matrimonial kin and their welfare including care when they are ill should be provided by their marital relatives (Sekese, 1991: 8). This understanding about filial obligations is still predominant among families. Arguably, the finding that blood-kin were primary caregivers of most married female patients to some extent suggested deviation from this cultural norm. The caregivers' experiences regarding neglect of the patients explicitly pointed out that at least among this group of kin, the patients were blamed for their illness; therefore the sick role was not facilitated (Lupton, 1994). There were subtle and explicit hostilities which seemed to be the result of the perception that the in-laws neglected the patients yet they would have provided care for their dead husbands. This pattern, although based on a small number of respondents, might suggest that HIV/AIDS stigma was likely to affect married women's care more negatively than men with the latter facing less severe sanctions from their families for a disease which in some people's view is self-inflicted. While there is consensus that emotions such as empathy lead to altruistic behaviour, the sociobiological viewpoint suggests that people are more likely to assist those who they regarded as kin (Piliavin and Charng, 1990). Although kinship would normally include those who are associated through blood and marriage, it may be argued that where both are involved blood supersede marriage relations. Consequently, there is a possibility of "the bystander effect, namely, that the knowledge of the presence of others who might help inhibits intervention in an emergency" (Piliavin and Charng, 1990: 35). They associated the in-laws' behaviour with AIDS stigma hence providing care was intended to challenge the stereotypes which led to the patients being denied dignity and treated as sub-human (Link and Phelan, 2001; Poindexter, 2005).

The African family may remain 'extended' socially and culturally, but economically the process of 'individuation' is salient. And, ordinarily individuals depend on nuclear family resources for care (Baylies, 2002) and increasingly scholars recognize that the family may not be resilient to the epidemic because the family members may be unwilling to provide support where illness is associated with HIV/AIDS (Baylies, 2002; Seeley et al, 1993) and this tendency has also been observed elsewhere (D'Cruz, 2002). Furthermore, the traditional kinship mechanisms of coping may be '*over-extended*' due to widespread poverty, urbanisation and AIDS-related chronic illness in families (WLSA, 1998; Crewe, 2002; Ellis, 2005). In Lesotho, families are experiencing unprecedented levels of poverty and declined welfare because of HIV/AIDS and labour retrenchments from the South African mining industry. Some of the possible effects of these changes at family level are loss of labour and skills of caring for the chronically ill with children and the elderly providing most of the care with limited resources. Poverty has negatively affected inter-household coping mechanisms (Turner, 2003) which suggests that the 'glue' that holds households together has changed and is no longer as strong and dependable. This may be compounded by the process of individuation and dependence on the cash economy. HIV/AIDS is an expensive disease (LeBlanc, London and Aneshensel, 1997) and its care has far-reaching implications for household economic resources (D'Cruz, 2002; McIntyre, Thiede, Dahlgren and Whitehead, 2006). But, the family members who feel strongly obliged to provide care may not consider costs over care.

The social embeddedness of illness went beyond initiating help at home. As the disease progressed and the patients became increasingly dependent emotionally, cognitively and physically, caregiving extended to the provision of companionship during clinical consultations (Andersen, 2004; Thomas et al, 2002). This behaviour was consistent with the typical response of family members when illness is life-threatening and normally their presence would not be inhibitive to the doctor-patient interaction. In fact empirical evidence suggests that the presence of family members influenced the quality of the medical encounters positively because physicians tended to provide more information on treatment and the symptoms (Labrecque et al, 1991). Also Labrecque et al (1991) and Blanchard et al (1996) indicate that family members' presence during consultations may be seen as an indirect indicator of uncertainty about the future and the distress experienced as a result of severe symptoms in cancer care.

The caregivers were extremely concerned with knowing the cause of the symptoms and the severe illness. Diagnosis was pursued as an integral part of obtaining medical treatment but some caregivers actively sought diagnosis from the hospitals because they were concerned that there was more to the symptoms and 'needed to know what they were dealing with'.

Sometimes they disregarded explanations which already existed because they perceived them to be inadequate. Perceptions about the credibility of the diagnosis which did not specify HIV/AIDS was influenced by awareness of the disease and 'its symptoms' as understood within the socio-cultural context, provided by the media and public health education. Therefore, certain symptoms were closely associated with HIV/AIDS and it would take medical diagnosis and effective treatment to discount these lay beliefs. In addition, the commonsense understanding was that the doctors and patients adhered to confidentiality to prevent family members from knowing about diagnosis where HIV/AIDS was involved – both were evasive about diagnosis. The result was pervasive suspicion that the illness was due to HIV/AIDS even though HIV would not uniquely announce its presence in the body at the onset of illness and it took time before the symptoms could be linked with the epidemic.

Consequently, the emphasis on searching for diagnosis was unusually prominent in the study given that literature on professional help-seeking behaviour accentuates seeking medical treatment (Nilmanat and Street, 2004) and little weight is put on the 'sociology of diagnosis'. For instance, they were more conscious and skeptical about diagnosis when the symptoms did not disappear following treatment or if new ones developed. Therefore, medical consultations were made because the caregivers perceived the symptoms unusual and were eager to establish the cause of the symptoms which they found troubling. Mechanic (1992: 1347) notes, "[t]he intensity of this search process depends on the apparent seriousness of the symptoms, the degree of discomfort they cause, and their persistence and course". For many caregivers the search did not cease because the symptoms were puzzling yet the healthcare providers provided the impression that the illness could be ordinary. Their illness experiences did not match the ordinariness portrayed by medical diagnosis.

Knowing the diagnosis was considered important for practical, emotional and existential reasons, and medical knowledge was expected to deliver accurate analyses yet it contributed to the difficulties encountered in caregiving. At the practical level, the caregivers considered it essential to know what they were dealing with. Perhaps such information could help reduce the risk of HIV infection. In caregiving, the caregivers have to deal with the emotions of the care-recipients and their own while also addressing the patients' practical needs

(Thomas, Morris and Harman, 2002). It was also considered a prerequisite to effective medical treatment, and the doctors had to be thorough. When improvement was not realized within a reasonable time the caregivers questioned the accuracy of previous diagnosis. Many recalled the various diagnostic procedures (x-rays, pathology tests and analysis of bodily substance such as blood and sputa) conducted during medical consultations some of which they specifically requested, and had confidence in them yet they sometimes doubted the outcome. In other instances the caregivers were disappointed and annoyed by what they viewed as 'diagnostic errors' by the healthcare professionals. They had different interpretations of the experienced symptoms from the clinical diagnosis and their doubts would be intensified when the healthcare providers expressed uncertainty about the cause of illness or shifted from one form of diagnosis to another. Sometimes the caregivers requested a review of diagnosis and suggested different explanations for the symptoms and expected the doctors to confirm them clinically. This was common where the patients experienced pains in the upper cavity, especially in the chest, or advanced AIDS symptoms. Chimwaza and Watkins (2004) note that in attempt to keep the AIDS diagnosis from the patient's relatives, health personnel mentioned lack of blood, diarrhoea or tuberculosis as diagnosis.

Diagnosis is the essence of the biomedicine and it benefits the physicians by giving them capacity to manage individuals' care and treatment, and the patients by "provid[ing] personal, emotional control by way of knowing what is wrong" (Brown, 1995: 39). It would appear that it was equally meaningful for the caregivers in that it empowered them with knowledge which was relevant for caregiving. The expectation that the technologies would provide thorough examination and produce scientific and objective results was understandable (Armstrong, 1995; Lachmund, 1998; Lupton, 2003; Van der Geest and Finkler; 2004). Armstrong (1990, 1995) pointed to a distinctively unique form of 'medical gaze' in the nineteenth century, whereby the hospital became the central place where sick bodies were investigated and treated. The caregivers did not expect clinical outcomes to be communicated in uncertain terms; this could be because doctors rarely express uncertainty even though it is integral to medical practice (Hatt, 1998; Whyte, van der Geest and Hardon, 2002).

It would be expected then that any problem-oriented endeavour would require actors to understand as much as possible the nature of the problem and failure to produce desirable outcomes has been identified as a form of stressor (Thoits, 1994). Some actually believed that there would be less muddling and emotional distress if they had reliable information. Sharing of information with caregivers in the management of chronic illness has been argued for in different disease contexts (Blanchard, Ruckdeschel and Albrecht, 1996; Haug 1994; Rajaram, 1997). The transfer of the information pertaining to the illness of patients in home-based care from the health providers to caregivers is an important aspect of continuity of care (Woodward et al, 2004). This value proposes the expansion of a traditional doctor-patient relationship into a triadic partnership with the caregiver, which is currently prevented by anticipated stigma in the case of HIV/AIDS. The emotional distress that arises due to a diagnosis of life-threatening illness such as cancer (Gotay, 1996; Blanchard et al, 1996) and HIV/AIDS (Nilmanat and Street, 2004) means that the support from the physician through information is indispensable as the family members try to cope with the illness. It was also important that the caregivers interpreted the dyadic relationship as dubious and associated it with the recent time and 'the new disease'.

Delayed caregiving raises important questions about the caregiving discourse especially the way it has characterised home-based care. The 'carer discourse' (Heaton, 1999) evolved in the developed societies through the 1980s and the 1990s and gained prominence in the Sub-Saharan Africa countries as a result of the HIV/AIDS in the latter half of the last decade (Mupedziswa, 1998; Jackson, 2002; Van Dyk, 2001; Uys, 2003). This discourse emphasizes the role of the informal caregivers in maintaining the wellbeing of the people in need of care at home and ignores the role of the chronically ill towards their own care. This is the case with PLWHA and could be attributed to the global concern to protect their human rights in a largely intolerant world. Nevertheless, the emphasis on a medical principle which assumes autonomy and independence inadvertently disregards the dynamics of HIV infection; that being HIV-positive is transitory and the need for care is intrinsically linked to the certainty about illness. That medical care retreats where cure is not realistic (Ministry of Health, 1993; Twigg, 1998; Kuhse, 1997) is a reality, but availability of informal care may also not be guaranteed.

The ethic of care emphasizes relatedness in caring and Noddings (1984) argues that in actual fact the relationship of the care-recipient and caregiver is intrinsically based on their mutual dependence and that its sustenance depends on both parties, with the 'cared-for' playing a distinct role in these relationships. This philosophical outlook could be relevant in HIV and AIDS home-based care because it seemed the caregivers struggled to be incorporated into the care relationships with the care-recipients and into the healthcare provider-patients relationships because of the emphasis on confidentiality. We should be skeptical of the universalism of the western values such as confidentiality because there are alternatives to orthodoxy (Noddings, 1984; Tronto, 1993; Kuhse, 1997). In the African context, the view that a person is less seen in atomic existence than in social relatedness is usually encapsulated by the *ubuntu* philosophy. It seemed that there were inherent contradictions between the caregivers' intention to do *ubuntu* and confidentiality. The traditional value system, which observed communality and sharing among kin members as fundamental to the well-being of the people including collective response to illness and disease is documented (Sekese, 1991; Machobane, 1999). What may not be clear is how western medicine adapted to this value system since its introduction in Lesotho. But there is historical evidence regarding the collective response of the Basotho to the colonial strategies for leprosy control which were influenced by racism and stigma at the dawn of the twentieth century. The seclusion of lepers in a sanatorium and surrendering the patients to the institution faced severe public resistance which culminated in mutiny because they alienated the patients from their communities (Machobane, 1999). The people accommodated the patients despite the fact that leprosy was perceived as contagious and disfiguring.

Confidentiality as practised by most health workers was not "based on tradition and particularity" and did not consider local wisdom (Nussbaum, 1995 cited in Kuhse, 1997) and instead encouraged the care-recipients' isolation. Moreover, the explanation that one of the main obstacles to home care may be the absence of willing and able caregivers (Williams, 2002) seems inadequate because the potential of patients with a chronic illness to contribute towards ensuring availability of carers may not be ignored in societies where democratic values of participation are emphasized. Failure by both the patients and the healthcare providers to communicate the HIV/AIDS diagnosis openly deprived the caregivers of the knowledge which they needed to execute care. These circumstances created peculiarly poignant experiences for the caregivers because inability to obtain reliable medical diagnosis created stressful caregiving situations. Consequently, the caregivers retold what Frank (1995, cited in Gwyn, 2002) named the "*chaos narratives*" of illness experiences which mainly defied most of the expectations about how the ill individuals and the healthcare providers should behave as well as giving impression that orderliness will be restored. They were distressing accounts of managing chronic illness in which most of the events unfolded in an unpredictable manner.

CHAPTER FIVE

EXPERIENCES WITH SEEKING HOSPITALIZATION

I think that it is much better when she is here at home. But it is only better when she is not too ill; when she is too ill I feel she should be at the hospital... (Sibling)

She was never hospitalised... I took her to the dispensary again. (Mother2)

In the twentieth century health care provision in Lesotho yielded to hospitals as providers of both in-patient and out-patient health care and the notion that very ill patients belong to hospitals was increasingly becoming a norm. Culturally, care for the ill was provided within the domestic sphere by the family members and the traditional healers provided medical treatment. Occasionally the sick person would reside with a healer temporarily and be released to be cared for by the family members while the healer maintained contact. Biomedicine encroached areas of life and conditions which had culturally been dealt with in non-medical ways thus indicating what has been termed the medicalisation of life. For example, pregnancy, childbirth, child health, and chest pains experienced mainly by adults and which were culturally interpreted as *sejeso*[1] became issues of biomedical concern. Hospitals played a crucial role in the treatment of acute, chronic and curable long-term illness. In fact, as part of promoting health, members of the public were actively encouraged to seek hospital treatment. It has also been noted that biomedicine responded to its incongruence with the cultural interpretation of illness regarding efficacy of treatment by over-prescribing, prescribing of placebos and over-use of injections (Ministry of Health, 1993).

Furthermore, in terms of the process of care, there was a direct relationship between the severity of illness and hospitalisation of patients. It could be predicted that a patient who attended an out-patient department at hospital was not seriously ill. The consultations could change in terms of frequency if the illness worsened and would ultimately lead to hospitalization – shorter or lengthy periods of hospital stay which led to 'cure' mostly. Hospital-based deaths were also common because people would usually transfer critically ill

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[1] Sejeso is a cultural illness indicated by coughing, weight loss, vomiting, sweating and loss of appetite. Public health has re-educated and persuaded traditional healers to be circumspect when their patients have these symptoms and should refer them to hospital for a free TB treatment.

patients to hospitals even if it meant dying in the hands of the medical personnel. In this way family members did not shoulder much of the responsibility to care for individuals, especially when they were severely ill. For over a century, biomedical and hospital care became part of the life of Basotho.

The resurgence of home-based care in the era of HIV/AIDS transformed the practice of health care in modern Lesotho and reduced families' access to hospitalisation. Increasingly, people with HIV/AIDS-related chronic illness are cared for and die at home. Ideally, home-based care should not take place without medical support and the patients should not be confined to the home regardless of their care needs. The question of how the caregivers experienced the implementation of the home-based strategy by the hospitals is pertinent given that the medical treatment approach followed in the care of PLWHA was "a minimum package of care" (Government of Lesotho, 2002) and would not prevent frequent illness effectively. Given that Basotho have a long history of hospital-based care, categorising an illness as chronic would not automatically prevent the caregivers to seek hospitalisation when they experienced life-threatening symptoms. This is illustrated by the similarities of the health-seeking behaviour of the caregivers in terms of the circumstances which led to them seeking hospitalisation for the patients.

In this chapter the experiences of the caregivers will be explicated using the notions of "continuity of care" and "demedicalisation". It will be argued that the caregivers perceived the patients' access to hospitalisation as a form of social support while in home-based care. However, despite the frequent episodes of illness, they did not always seek hospitalisation though they expected their relatives to be hospitalised when the intensity of the symptoms exceeded their tolerance threshold. They responded to the needs of the care-recipients in similar ways but the hospitals responded differently depending mainly on whether the caregivers sought hospital care on the basis of HIV/AIDS, TB or other ill-defined illnesses. In most situations, there was poor communication regarding the implication of the diagnosis and prognosis for the patients' care. Consequently, there were varying degrees of medical support in the form of hospitalisation and this feature was crucial in determining continuity of care and alleviating or exacerbating anxiety in caregiving. The caregivers' encounters at the hospitals could also produce the feelings that the patients were treated differently because they were diagnosed with HIV/AIDS while their admission into the hospitals was seen to be jeopardised by the symptoms they experienced at the time of consultation. Also, it will be argued that restricted admission to hospitals during severe illness was one of the manifests of the demedicalisation of AIDS care because, whether intended or not, it reduced 'dependence' on medical and professional care while the involvement of the family members in care was emphasised. The caregivers' experiences illustrate how the families were affected by the practices which the hospitals adopted to reduce the burden of institutional care prompted by AIDS.

Awareness that the illness was chronic

While the caregivers were aware that the care-recipients spent a long period ill, many were vaguely informed about the implications of the illness for their involvement as caregivers and the home as a place where much of the patients' care would take place. This was because the doctors rarely communicated such information explicitly to the caregivers. As a result they tended to have different degrees of understanding and expectations about prognosis yet their common experience was that the care-recipients fell ill frequently and maintaining contact with the hospitals was necessary.

A caregiver who knew about the nature of the illness from the onset said:

> *I don't know, but when she becomes ill I become discouraged even though I was told that she was going to be ill most of the time. They didn't hide it from me. They told me at the hospital that as I know there is no cure for this disease but they will try to fight TB and these other infections, but even though I know all these, it becomes painful to me when I see her falling ill frequently. I want her to live well even though the infection is there in her body (Aunt)*

Sometimes the expectation was that treatment would bring lasting improvement. One caregiver stated:

> *There were times when she would be better but just for a while and there were people (health workers) from the hospital who would pay her visits. She would become a little bit better but she would not spend a long time still feeling healthy and it meant going to hospital, coming home, and so on. Before long she fell ill again, and we took her to the hospital (Mother-in-law)*

Another said:

> *She kept on going to the hospital and we would think that she is better but after a few days she would suddenly fall ill again* **(A-ea sepetlele re be 'ne re re ho ba betere, ha re re ho betere ebe ho boetse hore qhu! hape)** *(Mother2)*

Since the patients fell ill so often, one of the common experiences among the caregivers was the frequent hospital visits which resulted in repeated hospitalisation of some patients. This was in addition to the out-patient care which almost all the caregivers were involved in as companions of the patients. As some of them commented:

> *I think the major thing has been these several consultations at the hospital, this year alone we have already gone three times, I'm not counting last year because last year he was even taken to Maseru, this year alone, three times. It is troubling because you cannot rest. When you think he is better he starts again and this goes on and on (Father3).*

> *She was hospitalized in 2003. In 2003 alone she was hospitalized more than 4 times... She has been to hospital three times this year. The last time she stayed there for two months... She was later discharged after staying for two weeks. She fell ill again and she was admitted for the second time. She had diarrhoea and was also vomiting. She was admitted for one week (Father1).*

> *He was there twice... they helped him a lot. I think that is why he was hurt when they returned him the last time when we went...Now he doesn't want to go. (Spouse3)*

These consultations were also depicted as not only exhausting to the patients, but personally tiring too. One of the reasons they insisted that the care-recipients should adhere to medication was to avoid severe episodic illness which could lead to in-patient care at hospitals. A caregiver who was bothered by the care-recipient who had the habit of stopping medication whenever the external cues subsided said:

> *She became ill again after she was a little better for some time, but that was not for long. She had to return to the hospital, but this time I told her that she was on her own...I told her that I would not go to the doctor with her because there was no use – I was just wasting my time, because she doesn't take the medication. I said "you must feel how it is like to go up this steepness to the hospital walking on your own, to be hassled by the hospital staff who tell you to go from one place to another for various services yet you are not going to take tablets..." (Aunt)*

Despite not being formally informed about how care for the patients would happen the caregivers realized over time that there was change with regard to the admission of the patients to hospitals – it was not easily accessible to them. They realised that the perceived seriousness of the symptoms did not necessarily lead to hospitalisation as it would be expected. Readmission after they were discharged was also difficult.

> *But this is what they do these days when your patient is too ill, they sent him home. It was not the first time because they last admitted him in 2002, and that was it. All these times when he is ill, I take him, we come back and I do my part (Son)*

> *... And they did not say it (diagnosis) at the hospital but we could see but they won't tell you even if it is your child, they will just keep on sending you back home with this person... (Sister-in-law4)*

Negotiating access to in-hospital care

Usually the caregivers had expectations about the likely medical intervention in the hospitals. They had trust in the doctors because of their knowledge but consistently they saw doctors making disappointing decisions about hospitalizing the patients. In particular they expected the doctors to take their subjective evaluation of the patients' condition into account and admit them into hospital to allow close examination and monitoring of the body following diagnosis. It was a rare but pleasant experience when a doctor showed willingness to see the patient in the future by suggesting check-ups.

A caregiver, who had failed to secure hospitalization for one patient, had a different experience when a doctor encouraged her to take the patient to hospital whenever she deemed it necessary. Recalling this unusual offer she said:

> *The doctor had said whenever she complained about pain I must just bring her to the hospital; I should not wait to see if she would become better. We kept doing this, taking her every time when she expressed some pain until she said: mother now I am tired, it has been long time since you started taking me up and down, now I am tired, just leave me as I am. (Mother2)*

On the contrary, these assumptions were often not espoused by some doctors because severely ill patients were returned home. When a patient who was perceived as deserving hospital admission was declined, the caregivers attempted to negotiate admission either in the same hospital or in alternative ones. The following descriptions illustrate these dilemmas:

> *...when we were at the TB clinic I expressed my concern to the doctor about these daily trips to hospital; that the patient was really exhausted. The doctor told me that she would be fine, that it was fine; we should keep on bringing her... my mother accompanied her for these daily check-ups and I rested at home. That day, she was admitted to hospital and to show that she was very ill, they kept her for the whole month. They had never done it before; it is usually 15 days, a week or just a few days... (Sibling)*

A mother who experienced different support from hospital said:

> *I wanted the patient to be hospitalised, this child was very ill. No sensible doctor would let such a patient return home. This girl couldn't walk. And I told them that she was not even eating well but all they did was to give us medicines and I don't know what it was for because even the TB which they suspected I don't think it was there because they did not tell us anything and they said the x-ray was not working. I think they didn't care if she died (Mother2)*

A father said:

> *In December he became very ill and I took him to the dispensary. I wanted them to get him into hospital so that they could see what was causing him the pains…I know that doctors can place you in hospital if your disease is tricking them, and after a few tests they will find it… Thereafter we returned home. They gave him some tablets and we came home. Thereafter this child of mine could not even eat, I was aware that he was in pain. I returned him to the dispensary (Father3)*

Circumstances under which caregivers sought in-patient care

Generally, the caregivers preferred to care for the patients at home or it simply did not bother them. However, there were mainly two circumstances under which they considered hospitalisation necessary. Firstly, there were symptoms which they found too distressing, For example, chest pains which 'caused' difficult breathing, diarrhoea, weak blood (anaemia) inability to eat and vomiting caused concern. When they perceived the patients to be in unbearable pain or discomfort and considered their own skills inadequate to alleviate the perceived suffering, they usually felt anxious that death was imminent; and sought medical support. Secondly, they considered hospitalisation when they subjectively assessed the symptoms to require specialised medical care by the doctors – certainly not nursing care because they thought that it was inadequate in the hospitals – or the medical technologies which were not transferable to the home sphere. The following excerpts illustrate some of the conditions and experiences which made the caregivers consider hospitalisation of the care-recipients.

One caregiver summarised this perception thus:

> *I think that it is much better when she is here at home. But it is only better when she is not too ill; when she is too ill I feel she should be at the hospital. You see when she is at home and she is too ill and she does things that I cannot understand, I don't know how I can help her so we need the hospital. But when she is at the hospital it is not like you have peace of mind because apart from not seeing how she is doing with her illness, you are worried about her general condition, those things that nurses don't like to do. But you have this hope that being in hospital means that she is close to doctors and a doctor will help when she does those mysterious things which we don't know how to deal with at home and there will be some changes that will allow her to come back home better (Sibling)*

This was because there were some care needs which they could meet better at home than in hospital. A caregiver who recognized the benefits of home care in this regard said:

> *I wanted her to go back to hospital even though I did not intend to leave her at the hospital; I simply wanted her to see a doctor and come back home...I felt that the hospital had done me a favour by bringing her closer to me. You see when she was in hospital she would complain about things which I felt I could attend better at home. She complained about cold when she was in hospital. I had to bring her an extra blanket. But as soon as she got home she requested me to make fire inside the house especially in the morning because she was feeling cold and needed warmth. I would heat water and pour it into a one-litre bottle which I wrapped with a towel and placed inside her blankets... and immediately she fell asleep, I would close the door... (Mother-in-law)*

Another said:

> *When he is not very ill, it is easy because he is not in pain, but when he is very ill, even these children become miserable. And there is no where I can hide them. They become troubled. You see they have seen a lot in this past year and I think all of us [in the family] we don't want to think about someone being ill. (Son)*

Overtime, the caregivers learned to observe certain patterns which consisted of a series of conditions which eventually led to physical changes which were intolerable and aroused fear. It was encouraging on their part to know that the hospitals would take over when they were overwhelmed by the care-recipients' symptoms. One stated:

> *When she cannot eat, that scares me a lot. Also when she vomits it makes her weak and when I see her that weak it worries me because you will see that even her face is not showing signs of peace at all, she is not happy, she does not even talk, her face changes. This usually happens after she has complained about headache, when she mentions that headache, I know that vomiting will be next, and suddenly she changes, her face becomes sad and she loses strength. At this point I know I should take her to hospital because for the last five months that I have been living with her I have observed some things which help me realize when she needs to go to the hospital (Sibling)*

Another said:

> *There are times when he is very sick and he refuses to eat every thing...But what we do when we see him in this condition, we take him to the hospital. They will discharge him when he feels better. This hospital helps us a lot especially because ADP helps with the payment of hospital bills; they pay for everything (Uncle1)*

Another caregiver who preferred consulting the hospital because it was the 'right' place to detect the cause of chest-related complaints was fulfilled when the patient was admitted when she consulted the hospital for the first time. From her past experience, this particular hospital was effective. She stated:

> *I was happy when they hospitalized her because I find that it helps many people...but he [husband of the care-recipient] wanted to try one doctor whom they had been seeing... I think I like hospitals, especially this one at [...], they help people there... I was insisting on the hospital because she was*

> *talking more about the pains in the chest and private doctors don't have x-rays, that's all. I was thinking that sometimes they say TB hides and since she only went once, may be when she goes for the second time they would see something different. (Sister-in-law1)*

Another caregiver recalled:

> *... She went back to the clinic after another week we went to Leribe government hospital because what we were looking for was hospitalization. We were hoping that she would be admitted and then given drips so that her blood and water in the body could improve. She was very weak. But even at [...] hospital they did not admit her they gave her tablets again and we came back home, very disappointed. (Mother3)*

A caregiver who contemplated the hospitalisation but did not have money for hospital fees mentioned the worrying symptoms and said:

> *I had really wanted to take him to hospital at some stage when he started to show things which I had never seen him do – the diarrhoea worried me because although I tried to give him a hydrant I saw that he was losing lots of water. But I could not because I did not have money. At that time the hospital was not telling people that when someone has this infection, the patient could be taken to the hospital for free. We thought that he would need money to be admitted (Spouse2)*

Sometimes the pain was overwhelming and unbearable but inexplicable. It caused anxiety and led them to consider hospitalisation. A caregiver said this about a son who had initially failed to be admitted despite being in severe pain:

> *At this time he could not do anything because he said his whole body was aching – his feet, his waist and chest, everything. He was crying with pain. I took him to the hospital again and they took him into hospital, this time they said he had accumulated a lot of water in his lungs (Father3).*

Another said this about the extraordinary cough which triggered seeking hospitalisation:

> *The first time when she was admitted she was coughing, I mean coughing. I had never seen anything like that and I was wondering, what could have happened to this child. And she complained about pains in the chest... At the hospital they tested her sputum and found that she has TB. They then admitted her. She was later discharged after staying for two weeks (Father1).*

Another caregiver indicated thus:

> *She became very sick again. I had lost hope about her, completely. And since she does not pay any fees at the hospital, I just make sure that I get her money for transport to the hospital and that makes life easy for me. She went to the hospital because at this time she was complaining about the genito-urinary system problems, she could not walk. (Aunt)*

Some caregivers considered hospital care even when palliative care was more relevant. Some caregivers said this:

> *...she took me by surprise; this person took me by surprise. But I wish she could be at the hospital... I think my mother fears that she might be rejected at the hospital because she is too ill. I don't know but we are doing everything to comfort her. May be if we had gone to hospital the same day she began showing me these unusual behaviour, but I thought that I should wait for my mother but she is not talking any more, just this moaning that you hear... (Sibling)*

> *At the beginning of the week she complained about a cold, she was coughing a lot. When she fell ill again I moved to her house because I feared that she would die with just me in the house. I don't know what is supposed to be done when someone dies so I took her to the hospital...When we got to the hospital she was admitted, the following day she died. (Aunt)*

Experiences when hospitalization was not secured

There were care-recipients who could not be hospitalized yet the caregivers perceived it necessary because the symptoms were life-threatening. Some were not hospitalised for the entire caregiving career of some of the participants while others were occasionally successful in negotiating in-patient care. A caregiver who could not secure hospitalization for a patient who she believed was at the brink of death described her emotional response during the initial consultation when the patient was not admitted. She said:

> *When she was first diagnosed [with HIV/AIDS/TB] I took long before accepting. When I was told by the doctor to take her home I cried. I was confused because I said how do I take this girl home, how do I look after her when my child is so little, my baby was two months old. She was very ill when the doctor said I should bring her home, I was expecting that she would be admitted (Auntie)*

Incidents when this form of care could not be obtained were painful because the decisions could also be linked to stigma and arouse suspicion that the doctors had a hidden agenda.

> *Can you see him? His problem is people. He did not want to go to the same place repeatedly. I tried to show him that the private doctors were not going to help us but he refused because of late he does not like to go to hospital. Before he was too ill, he would go and they hospitalized him twice, but later they did not hospitalize him, we would go and come back ...I think that was the part he did not like; he said if they were going to humiliate him by moving him up and down he would rather stay home. He refused so when he is too ill I just decide that I will take him to hospital because people don't understand, they look at me and think that I am neglecting him, even his family would talk. It is my major problem because I tell him he needs medicines and he knows that... (Spouse3)*

Another caregiver was adamant that a doctor was less interested in helping the patient but emphatic on testing his blood instead:

> *He was very ill… the doctor said we should go for blood test and they also gave us the bottles so that he can take his sputum to the hospital…The doctor did not admit him, I was hoping that they were going to admit him but he only talked about blood tests…It was painful because this is our hospital and if your patient cannot be admitted where else do you take him. Even outside here people talk about us. You people give others names? They say we are an AIDS family which is ok because Basotho were not wrong when they said:* **motšeha lefuma o oa ipitsetsa**…[Translates as: If you ridicule someone today, tomorrow it will be you] (*Son*)

Another caregiver who also realised that diagnosis and the physical condition of the patient did not influence the doctor's decision even after she had expressed concern about the deteriorating health of the patient, said:

> *I was thinking maybe this doctor can see that she is going to die, and she knows that if she keeps on walking there everyday she will be tired and finally die, because I did not understand because they say TB patients need to rest because their lungs are damaged. She returned us home. When we got outside the hospital she could not walk any further. I thought that maybe she needed to eat something. I forced her to drink milk she took a few sips but she still could not stand up...and people were watching... we walked slowly home; it was difficult because we had to walk, stop, walk and stop again until we got home…The patient could not speak at all. It was tough…And you meet people who ask with curiosity: "but why have they not admitted a patient so ill?" and you know what they are thinking already…AIDS. They just want to test you, and that is one thing that really annoys me. When people see a patient who is very ill but is not admitted to hospital, they put 2 and 2 together and they say it must be AIDS. I don't really care when people know, my family never made it a secret. But it is painful when people think that she is not admitted to hospital because she has AIDS, it hurts me because to me it is like she is not like others…. I don't know but I hated them for what they did to us. Right now I feel reluctant to take her there… (Sibling)*

A mother said:

> *…they tested and they couldn't detect TB – I think it was hiding because she coughed to the end. They did not hospitalise her, they gave her some cough mixture and tablets and I returned with her even though she had very strong spasms which I was afraid would suffocate her anytime. The problem was the x-ray; there was no water at the hospital so she could not be examined. (Mother3)*

Failure to secure hospitalization was experienced painfully. Sometimes the caregiver convinced reluctant care-recipients that the hospital was the right place to be or that hospitalisation would provide specific treatment. A caregiver who was disappointed by being turned down said:

> *I think the major one was persuading her to go to the hospital because she was so hooked to the private doctors. They are expensive but the medicines which they gave her were not making her better… I convinced her that if she could be admitted and get blood [transfusion] she would be better, it was my song everyday, I persuaded her. I was disappointed when she was not admitted and I think she lost hope and that affected her badly … When the doctor did not suggest hospitalization I got discouraged and I wished I could say something… She became extraordinarily quiet thereafter. For days, she would only speak shortly if you talked to her...I was also worried … She spent most time sleeping… You know why I was saying she should go to the hospital. Her skin has become*

> *very dry. I am the one who helps this person everyday and I see these changes on a day to day basis. It is still dry even now. I was hoping that if she went to hospital she would get a drip... (Daughter)*

Feeling rejected also introduced new challenges in caregiving in the sense that it usually led to the care-recipients being pessimistic about their chances of recovery and doubting any efforts to help them get better. It was common for the caregiver-doctor-patient interaction to affect caregiving because the caregivers were saddened by the patients' loss of hope and depression emanating from being rejected from the hospitals.

Hospitals did not admit patients with specific conditions

It was a common understanding that highly dependent patients were not admissible into hospitals. In some instances the caregivers were convinced that the patients needed to be hospitalized but would not attempt to take them to hospital because they had the symptoms which the nurses were said to loathe – such as lost functional independence and diarrhoea. A caregiver who was referred to hospital by a nurse at a local clinic was equally disappointed when they were refused admission despite supporting referral records:

> *...we took her to the clinic and the nurse wrote a referral letter to the hospital saying that it seemed she did not have blood and water in her body system. She went to the district government hospital the following day... they told me that they would not be able to admit her because she had diarrhoea... She was very weak. But even at [another public hospital] they did not admit her they gave her tablets again and we came back home, very disappointed. I could not understand how these people would not admit this child because she was very ill. When we went so that she could be admitted so that she could have a drip they refused saying she would have to treat the diarrhoea at home first. What kind of hospital is that? And when we left I was angry...It was painful but at the same time I said that doctors know when they cannot restore health again. I had already heard the nurse and the doctor saying that there was no life in her, so I just thought that everyone was seeing it as a waste of time... I wish that doctor at [...] could see her now... he read her health record book from the clinic and it was clear in the book that she had to be hospitalized, so when he suggested otherwise what could we do? (Mother3)*

Some of the caregivers indicated that patients who were not functionally independent or had diarrhoea would not be admitted unless there was a family member to assist such patient – it was not worth trying.

> *She could not walk on her own anymore, we had to carry her, and she could not even sit. I realised that since she could not even sit on her own she would cause problems at the hospital... (Mother2)*

Another caregiver who expressed her dilemma with a patient who she knew would not be hospitalised because apart from not being ambulant the patient had persistent diarrhoea, said:

> *Now her problem is how to get to hospital because at this moment she cannot walk any more, this is the difficult part. But even at the hospital they will return her. In this condition, they will because they don't admit people who are this sick. I don't know what can be done at this stage (Sister-in-law2)*

Another said:

> *I was thinking that may be they did not want to admit her because she had diarrhoea. I thought that since patients who have diarrhoea are associated with these latest illnesses – HIV/AIDS, probably the doctor did not like that (Mother3)*

At a certain stage, hospitals ceased to be an alternative place for care because the caregivers lost hope that any treatment would improve the condition. They avoided possible rejection by the hospitals when they anticipated it. A caregiver who did not hope for admission because the patient's symptoms were likely to lead to denial of hospital care ignored the suggestions to take the patient, who died shortly thereafter, to hospital because she believed it was unnecessary. She cautiously said:

> *You know some of these things we don't want to talk about because they are terrifying.* (Looked at me for sometime before continuing – then said) *it doesn't matter because he is resting now. His genitals were completely removed.* (Another long pause) *His father could have found this because I used to give him [patient] a towel so that he wiped himself. But for these last two weeks he could not even hold a towel so I had to help him. I was shocked as you can imagine. I didn't know what to do because who could take someone like that to hospital? Those are some of the things that nurses don't want to see, they would sent him back home. Besides, already you could see that there was no life in him, it would be just bothering him because it would mean carrying him on the wheel barrow to the main road. His father suggested hospital but I just kept quiet because I could see that it was just a matter of time, just a thin thread that was remaining holding his life. I knew that he would not execute so I kept quiet (Grandmother)*

Experiences when patients were admitted

It took the caregivers different degrees of effort to obtain hospitalization when they felt they needed it. It was also obvious that some caregivers' relationship with the hospitals improved with time such that some of them realised that access improved after a while. And it was encouraging when they knew that their relatives would be admitted whenever they experienced distress due to the symptoms felt relieved when the care-recipients were admitted. But the caregivers had different experiences regarding the effects of this form of intervention on the health condition of the patients. These included significant improvements which many realized following hospitalization. However, there were times when their expectations were not met and the patients' condition did not change significantly. Only one caregiver reported that the care-recipient died while in hospital. In addition to the medical aspects, other experiences involved the form of nursing care the patients received and the thoughts which such treatment introduced.

Positive experiences

A caregiver who had earnestly requested the responsible doctor to admit a patient who could hardly walk between home and the hospital daily, said:

> *I felt relieved because that was what I had been pointing to for so long... But I think that after that incident they learned a lesson because last time when she was admitted it was not a hassle at all (Sibling)*

Another caregiver also had positive experiences after the patient was hospitalised and the doctors treated a problem which he believed would not have been identified had the patient remained at home. He said:

> *They drained the water [from the patient's lungs]. He spent three to four days at hospital... I found out when I got there visiting him that he was still in pain but he told me he felt better. And I felt encouraged (Father3)*

Many caregivers observed significant improvements which they attributed to the specific treatments which the patients received in hospital. Although in some instances they would not specify the form of treatment received during hospitalization, they noticed that the life-threatening symptoms subsided. Some of the participants described how devastated and hopeless they felt at the time the patients were hospitalised:

> *But I'm telling you, Hospital X brought her life back given the way she was when she was first admitted. The first time when she was admitted I was even afraid to see her, I had lost hope... She usually spends about 15 days there and she comes back. She is usually better and can do a few things chores ... (Father1)*

> *I took her to the hospital... She stayed for two weeks; she became better and was discharged. At that time she was very ill. I had completely given up about her life because she could not even breathe properly. She even gained some strength she could even get out of bed and sit outside in the sun... I was feeling encouraged. I thought that she was better again. But you can see how she is now... (Sibling)*

Another caregiver stated:

> *She was hospitalized and they gave her the 15-days treatment, the real TB treatment that I know and she was discharged with big improvement. When she was discharged you could see that she was alive... (Mother-in-law)*

> *She was hospitalized and she came back after two weeks. I was happy when they hospitalized her because I find that it helps many people… when she came back she looked much better because I even wanted to remind her of my advice to her which she didn't take at first but I decided, let me leave that. We were friends; apart from being sisters-in-law we liked each other very much. She looked much better and she was saying it herself. For two weeks she could walk outside and sit outside (Sister-in-law4)*

Negative experiences about hospitalised patients

Patients discharged early

However, improvement was a relative term because there were dynamics such as sudden relapse and incomplete recovery. The caregivers were unhappy to see the patients who were still in pain and could not function independently released to home. They blamed the doctors who made such 'inappropriate' decisions. It was discouraging to the care-recipients too and inefficient because the patients would usually be returned to the hospital shortly thereafter. Thus, some of the participants experienced these irregularities as follows:

> *…when he was in hospital he was in pain because even when they discharged him I was not happy; I was saying this child of mine is still ill. But I am encouraging him everyday so that he does not think about negative things because there was a time when he was always thinking about his children and wife and told him that there was nothing he could do, the doctors tried. His wife was hospitalized two times but she did not become better until she passed away… Even when she died she had been in hospital. But she was returned and we were told that she should be cared for at home (Father3)*

> *She was very ill at the time, even her being discharged was just done because doctors are doctors; it was still heavy… Well, it varies because you see sometimes they discharge her even though she cannot even walk; while she is still very weak. I wished they could discharge her when they realize that she is stronger and she can walk with minimum support because you know why, it becomes a problem when they release her and she cannot even walk from the hospital to the bus stop. It is discouraging to go out of the hospital with someone in that condition but as I said the doctors do it. Sometimes they discharge her like that and we get home I observe her for days and realize there is no improvement, so I take her back… (Sibling)*

Neglect and extending caregiving to hospitalised patients

Part of the reason some caregivers preferred to care for their relatives at home was the widespread perception that the patients did not receive adequate nursing care in hospitals. A caregiver indicated that despite the pain she felt when the patient was denied admission to hospital, in retrospect she appreciated this because she believed the patient could have died in hospital because the doctors and nurses had given up on her. She said:

> *It is a very difficult work because you are on your own most of the time and sometimes you don't even know what you are doing. But I still thank God that no hospital admitted her. I don't think she would be what you see now. She would be dead because no one was seeing any life in her. Nobody would persuade her to take medication and food; the nurses do not have time for patients like her. Maybe she could have been killed by the diarrhoea or even that constipation. Anything, but it was really difficult to get where we are today because you are helping her to be strong inside and outside. It makes you think hard because everyday you are confronted by death and life (Mother3).*

Various caregivers provided anecdotes about what had become a common practice in hospitals involving the expectation that family members should provide practical care – changing clothes, bathing and feeding the dependent patients.

> *When she was at the hospital they neglected her; they did not bother to go to the hospital to bathe her, and I had to go there myself and bathe her. I brought her clothes so that she could wear fresh clothes (Mother2)*

Another caregiver who attributed the care-recipient's illness to the infection from helping a relative who was hospitalised said:

> *We left this girl to help her mother because the hospital people said she needed someone to help her since she was very ill and could not do anything on her own; she needed someone to bathe her and so on. She then got infected by her mother... This is where we committed this mistake because she is now left with the burden of this disease. You see she was doing everything for her mother, bathing her and feeding her. The nurses only came to give medication...the entire burden was on this child. (Father1)*

This expectation meant that the caregiving role was sometimes extended to the formal settings, and for those patients who needed more vigilant care it was easy for this expectation to translate into neglect because the family members could only be present in hospital during certain times. Consequently, though they envisaged better medical attention for their relatives while hospitalised, they also worried about their emotional wellbeing.

One of the caregivers described the poignant experiences she had when the patient was neglected by the nurses while in hospital.

> *It was tough because she could not even eat, she could not bathe herself or feed herself. And she was at the hospital and we had to go every morning to bathe her because we had once gone there and found her in a mess ...we learned that she had not been helped to bathe the whole morning, we went lunch and dinner to help her eat and in the morning we bathed her or whenever we found her in a mess... she needed to be encouraged to eat and that needed time... she was just served food and later it was collected, she did not eat, so we took over. We helped her to eat three times a day for those two*

> *weeks. And, when we went to the nurses to get soap to bathe her nobody said anything, a nurse just gave us all the stuff (toiletries) including the gloves saying to us you must cover your hands…I could not understand why we had to do it when she was at home and when she was at the hospital. I wondered could it be because she has HIV/AIDS or is it because she does not pay the hospital and they know… I could not understand how they hoped she could go to the bathroom when she could not even get out of bed, she was weak and she had already fallen one day when she was attempting to go to toilet because she became dizzy… (Sibling)*

The caregivers would not consult the hospitals for every illness episode they experienced and most importantly, they did not always expect the patients to be hospitalised. They preferred their relatives to be at home whenever it was practical but also considered that the patients' care in hospital could not be guaranteed. They redefined the need to seek hospitalisation and would consider it when they perceived the symptoms overwhelming and life-threatening and felt that they did not have adequate competence to meet the care needs of the patients at home. The hospitals were trusted under circumstances of uncertainty. For instance, to secure direct observation by the doctors, to access specific medical technologies which could only be employed within the hospitals and the meanings the caregivers had about hospital-based treatment and its effectiveness for specific diseases. Their anxiety and expectation meant that the way the hospital personnel responded when the caregivers negotiated hospitalisation for the cared-for generated profound emotional experiences and had far-reaching consequences for caregiving. In particular, rejection exacerbated stigma and feelings of hopelessness, and doubts about the commitment of the doctors to treat the patients and prevent their death, while hospitalisation affirmed the caregivers in their role, alleviated their anxiety by providing some degree of certainty in what seemed a precarious situation, and provided them with respite.

The caregivers' success when they negotiated hospitalisation varied. Some care-recipients were never admitted despite the caregivers' several attempts but, others were admitted whenever the hospitals were approached with worrying symptoms. Most of the caregivers who benefited from institutional care in this way attributed their situation to the nature of diagnosis – HIV/AIDS and TB. But this does not mean that diagnosis *determined* hospitalisation. In fact, in all instances it was not possible at the beginning to have the patients admitted even when TB or HIV and AIDS were already diagnosed. Clearly, the severity of symptoms was also a poor predictor of hospitalisation since symptoms could also influence the chances of obtaining hospitalisation negatively. Access to hospitalisation diminished with the symptoms becoming more distressing. There were some care-recipients who were bedridden and would be in the last AIDS illness phase but there were occasions when the care-recipients recuperated while at home and they brought moments of pleasure and hope too.

Discussion

This analysis indicates that the caregivers considered the health care services including hospitalisation integral to home-based care, and maintaining the connection between the two spheres was always desirable and an essential part of caregiving. This situation was illustrated by the caregivers' actions when they experienced life-threatening symptoms, illness conditions which required specific medical treatments in hospitals and by their emotional experiences about the responses they obtained from the hospitals when they sought hospitalisation for the care-recipients. During their caregiving career, they periodically needed the patients to be hospitalised, but the care-recipients had different degrees of access to hospitalisation of the patients and such access was not dependent on their appraisal of the illness. As the care needs of the patients evolved the caregivers realised that hospital admission was unusually difficult while stays were also shortened. It was common for very sick patients to be returned home after consultation in the out-patient departments or to have them discharged home before they could recover.

To the extent that the home-based care strategy was emphasised with the role of families and community members in the care of chronically ill HIV and AIDS patients stressed, most caregivers were bound to encounter difficulties when they negotiated hospital admission for the patient. This is because home-based care is usually implemented through application of stringent measures which minimise hospital admissions and stays. However, the major shortcoming was that the medical drugs provided inadequate health support. Steinberg (2002) observed from a survey of households affected by HIV and AIDS in South Africa that there was a displeasure expressed in relation to hospital services because the patients were often discharged early and medical treatment was ineffective. The minimum package of care which included treatment of opportunistic infections could not prevent severe and unexpected illness episodes which usually necessitated hospitalisation. It was inevitable for the caregivers to have poignant experiences as hospitals aggressively implemented the policy despite the perceived care needs of the patients. Therefore, the critical issue for this part of the analysis was how the caregivers experienced hospital care as they attempted to maintain the continuity of care (Woodward et al, 2004) and as the care needs of the care-recipients changed but would not receive adequate medical attention because the illness was chronic and care was to a large extent demedicalised.

When life-threatening symptoms occurred, the most sensitive response was to seek hospital care. Similar behaviour has been reported in situations where heart attack symptoms (acute myocardial infarction – AMI) are experienced (Dracup, Moser, Eisenberg et al, 1995). In this study the actions of the caregivers could be seen as embedded in a socio-cultural practice that evolved over a long time in which the poor consulted government and church hospitals due to free health care services some of which precede independent Lesotho[2] and affordable health care (Turner, 2001). The concept of the health service area (HSA) also facilitated access to the hospital care level with little success by the PHC to avert the behaviour. It may be expected that care strategies which wean families from this service in the era of HIV and AIDS will be as catastrophic as the retrenchment of the Basotho males from the Republic of South Africa mines because people have limited options. This change was bound to be experienced negatively especially in the context of a volatile illness and limited communication of relevant information to the caregivers.

The caregivers continuously assessed the patients' condition and hospitalisation was preferred to home-care only if the symptoms caused distress or aroused the anxiety that they could lead to death. It seemed that they developed a tolerance threshold of the patients' symptoms which was not necessarily influenced by "values about independence and stoicism" as it would be suggested about the sufferers (Mechanic, 1968 cited in Morgan, Calnan and Manning, 1985: 79). Instead, they devised a framework of symptom evaluation based on their perception of what was life-threatening and therefore that which amplified death thoughts in their consciousness. Interestingly, most of the symptoms for which the caregivers expected hospitalisation were the conditions for which referrals are

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[2] As early as 1956 TB was among the public health problems for which colonial government provided chemotherapy and antibiotic treatment free in both government and church hospitals. See Basutoland, Annual Report of the Medical Department for the year 1956. Maseru. 1957.

recommended. These included difficult breathing, inability to eat, headaches which could signal meningitis, excessive diarrhoea and dehydration (van Dyk, 2001; Ministry of Health & Social Welfare and WHO, 2002). Accordingly, their health seeking behaviour could not be misconstrued as an indication of a dependency syndrome; in fact they were aware that hospitalisation was economically demanding while some were pessimistic about some aspects of the nursing care in the institutions. However, Granshaw (1989) indicates that it is a common practice in modern societies to transfer people who are severely ill to hospitals: "And few would doubt that the best place to be, if seriously ill, is in the hospital" (Granshaw, 1989: 1). Their expectation to obtain assistance from the hospitals might be understood from the fact that hospitals, as part of scientific biomedicine, evolved into powerful institutions providing treatment through the use of sophisticated technologies in modern times (Rosenberg, 1987). As suggested, hospitals remained the centre of health care activity for more than two centuries (Armstrong, 1995) substituting the home as the domain of care (van der Geest and Finkler, 2004). Lupton (1994: 94; 2003:101) suggests that while hospitals may be culturally unfamiliar settings for many people, they generally have a positive imagery because they are perceived as part of the scientific progress and "promise salvation and remediation for those who are ill".

In most African societies, hospitals were introduced through colonialism and missionary work thus becoming an essential element of the Western political project to conquer the world and replace the indigenous ways of life including the healing systems with western practices and institutions. Interestingly, Africans were more receptive of Western medicine than colonial rule and the pluralist landscape of health care systems found in many non-western cultures is a result of this receptivity (Good, 1991). Modern states continue to form synergies with church institutions to provide health care services through the hospital system (Good, 1991; Kimaryo, Okpaku, Githuku-Shongwe and Feeney, 2003). These relationships provided subsidized health care including hospitalisation for the majority of the citizens, including the poor. As a result, the notion that the ill belong to the hospitals was, until recently, a reality for most people and placing severely ill family members in hospitals to be 'cured' with medicine was a norm. The shift away from medicalised care is interesting when considering that there were many issues which Basotho had previously dealt with outside the realm of biomedicine but public health became a major tool through which these domains of life were redefined using medical terms thus leading to their medicalisation (Williams and Calnan, 1996). Failure to discern the institutional goal to keep the patients at home as long as possible led to the caregivers spending a long time attempting to negotiate hospitalisation.

The outcomes of their endeavours differed as some saw access improving over time while others negotiated hospitalisation in vain. The idea that hospital access is necessary for follow-up care and when the discharged patients are critically ill (Jackson, 2002) resonates with continuity in home care (Woodward et al, 2004). However, in the absence of a clear care plan for the patients, hospitalisation was not practised in a manner congruent with the needs and expectations of most caregivers in a predictable manner thus exacerbating their stress. When the patients were shifted into home care, there seemed to be inadequate planning, monitoring and review of their situation to ensure that they received undisrupted care (Woodward et al, 2004). In the case of the current study, planning would also benefit from involving a family member who would eventually assume the responsibility of care. Unsurprisingly, the hospital personnel were viewed as insensitive to the concerns of the caregivers and were sometimes suspected to act arbitrarily and arrogantly because of their knowledge while the caregivers felt powerless in these medical encounters. Contrary to their expectation, the caregivers also realised that the patients were discharged early. These patterns are consistent with the restructuring of the health care systems globally whereby the private sphere and informal relationships in the communities and families are important resources for care (Horwitz and Reinhard, 1995; Twigg, 1999; Cowen, 1999; Yamamoto and Wallhagen, 1997; Heaton, 1999; Mupedziswa, 1998; Sevenhuijsen, 2003; Uys, 2003; Williams, 2002; Woodward et al, 2004). For instance, Woodward et al (2004) observed that the home care sector was growing rapidly in Canada and identify some of the factors which have necessitated this trend as an increase in the number of people with chronic illnesses and physical disability and aggressive discharge plans and shorter stays in hospitals due to financial constraints that hospitals faced in the 1990s.

Sometimes the caregivers sought hospitalisation because they anticipated specific treatment interventions which could only be possible in hospital settings. For example, blood transfusion when they noticed anaemia signs. Various conditions such as clear eyelids and scaly skin were associated with insufficient blood in the body and therefore life-threatening. Blood is considered to have deep symbolic meanings in any culture – "as the source and symbol of life" (O'Neill, 2004: 69) and to give blood is a sign of empathy which could be equivalent to prolonging the recipient's life while denying it could be seen as hastening death or denying those who were brought for treatment a chance to live. Similarly, intravenous fluid drips were a procedure considered when the patients could not eat and were dehydrated. The caregivers' negative experiences when these procedures could not be accessed were not puzzling because as McInerney (1992) pointed out, fluids and foods in medical settings were seen as part of medical treatments, therefore withholding them from terminally ill patients was not only a moral issue but it was also emotionally disturbing to family members. In this sense, the caregivers sought these medical procedures as part of their help seeking endeavours. Consequently, inability to access these technologies was equivalent to being denied medical treatment, because their perception was that these procedures could prevent life loss.

Following an era in which medicine was acknowledged for its superiority in most parts of the world, debates arose in the developed societies about the ever-expanding jurisdiction of medicine into the various spheres of life and the relationship of medicine with the rest of society became contentious. The medicalisation thesis was summarised by Lupton (1997: 95) who pointed out that according to critiques in western societies, "social life and social problems had become more and more 'medicalised', or viewed through the prism of scientific medicine as 'diseases'". It is a long-standing critique of medical power by sociologists and it raises concerns about decreased autonomy of lay people to solve their health problems and exercise their civic liberties, relegation of patients' perspectives in medical encounters to insignificance, and inappropriate designation of social problems to medical categories (Freidson, 1970). This critique also emphasised the side-effects of medicine and the view that it was a universal remedy (Illich 1976 cited in Lupton, 1994) and its limited efficacy in chronic illness (Bury, 1997; Lupton, 1997). And we may add to the list: uncertainty which is suggested by the disparity in the categorization and diagnostic frameworks and types of clinical interventions made to treat disease (Hatt, 1998: 231) which is perhaps even clearer in the way the poor and rich are medically treated when they have HIV and AIDS.

However, there are also observations that economic consideration and lack of political will among the leadership shape policy responses to the epidemic which is highly dynamic and costly. Lawton (1998) points out that the acclaimed desirability of home-based care is "a form of rhetoric congenial to policy makers and planners promoted by them because it is a more cost-effective form of care" (p. 122). Therefore, it is difficult to conceive of the hospital admission patterns reported by the caregivers outside the larger project of rationing resources which in the case of AIDS care may be pursued by the promoting holistic health approach which manifests in the demedicalisation of AIDS care. For example, Nattrass (2004: 77) refers to the level of care provided to children infected by HIV which includes reduced or restricted hospitalisation as one way in which the South African government might reduce treatment costs – treating opportunistic infections within the primary health care level and the home as the main domain of care. Generally, the approach of the South African government policy for AIDS care – characterised by minimum medical treatment for opportunistic infections (Nattrass, 2004) – is similar to Lesotho's policy in many respects: the key feature being the unaffordable treatment discourse which in the long run introduced a certain degree of demedicalisation and emphasis on holistic health.

The notion of the holistic approach to care de-emphasises the role of doctors in the management of individual health. Although pharmaceutical products are used extensively, it is mainly with the purpose of preventing illness. Obviously, the approach is consistent with a care approach which reduces dependence on hospitals by promoting home-based care. At policy-making level, the 'holistic health' approach emphasised meeting the nutritional needs of the affected individuals and this gained prominence while ARVs were deemphasised. This link should not be misunderstood as suggesting that provision of food was a redundant policy response to HIV and AIDS; this is meant to problematise the idea of comprehensiveness in a situation where nutritional and medical solutions should be balanced but attention was persistently paid to one aspect. Additionally, some of the sentiments of home-based care as an approach to meeting the needs of the chronically ill suggested that the responsibility for health and illness was returned to lay people. Lowenberg and Davis (1994: 587) argue that holistic health certainly epitomises the process of demedicalisation which its advocates depict by placing tremendous emphasis "on returning the responsibility for health, illness, and cure to the individual". In this way home care is consistent with the values of demedicalisation which attempt to reinstate family care which is believed to be undermined by the medicalisation of the body (O'Neill, 2004).

Although demedicalisation (Lowenberg and Davis, 1994) of AIDS care could not have been an explicit goal of the home-based care policy in Lesotho, there were specific contextual factors which suggested that ultimately, one of its consequences was that care shifted to the margins of formal medical treatment. This seemed inevitable given the circumstances which usually lead to adoption of home care and its long-term goals. For example, Twigg (1998) observes that home care arises where medicine has failed to bring about cure. Unavailability of medical treatments in the form of a vaccine and cure globally, and unavailability of ARVs to the general population infected by HIV and AIDS are pertinent features of this care milieu. Other components include explicit rationing which is achieved among others by fee-for-service, restricted length of hospital stays, restricted test procedures and the use of drugs (Gross, 1998; Hatt, 1998). This care environment could further be complicated by a liberal ethos of *"We have no capacity"* which Kimaryo, Okpaku, Githuku-Shongwe and Feeney (2003) identify as an obstacle to delivering care for PLWHA at personal and institutional levels in Lesotho.

As some writers have indicated, to acknowledge the ideas expressed by the medicalisation thesis is not to suggest that societies can deal with the problems relating to health and illness without medicine (O'Neill, 2004; William and Calnan, 1996). As O'Neill rightly states,

> Rather, the question is whether we need *as much* medicine as we have, *for whom* we have it, and *for what* we have it, and whether we should abandon all paramedical and nonmedical practices that have hitherto served to cope with and interpret the ordinary ills of embodied beings (O'Neill, 2004: 68).

One would argue that HIV and AIDS is one of the health problems for which societies need effective medical interventions to prevent infections, improve quality of life and delay death. The high level of social disruptions inherent in HIV and AIDS, especially at family level as a result of chronic illness which is likely to affect several family members and bring about distressing illness and mortality of young adults within a short period of time, and the complex threats the epidemic poses to the social reproductive role necessitate this. Periodic hospitalisation of very ill patients would provide respite to family members while effective medical treatments continued to be administered. The epidemic has compelled the western societies, where the medicalisation/demedicalisation debate originated, to recognise the extraordinary nature of AIDS and embrace medical interventions as core to dealing with the disease. The proliferation of pharmaceutical products produced by multinational corporations in the West and what various scholars (Karasz, Dyche, and Selwyn, 2003; Persson, 2004) identify as the transition that occurred in these countries towards the intensification of HIV and AIDS drugs especially HAART illustrate the significance of drugs. The societal consequences of these developments in terms of enhancing the imagery of medicine and reducing deaths have also been realised.

The caregivers' descriptions suggest that continuity of care was experienced differently and this depended on how responsive the formal health care institutions were to the care needs which emanated from the home sphere. The caregivers who accessed hospitalisation when they envisaged it found the health care personnel supportive and sensitive. They expected the health care professionals to affirm the role they played in linking the patients with the health care system and to trust their judgment regarding the illness situation, especially their assessment that the care-recipients would benefit from hospitalisation and direct medical observation. The realisation that their opinion mattered enhanced their sense of competence and empowered them while their stress was also alleviated. Since each subsequent illness episode usually marked further deterioration in the health condition of the care-recipients, it would be expected that their uncertainty and anxiety also intensified. But from the care perspective it was critical that their actions led to addressing the recognised gap and ensuring continued care. Various care theorists (Tronto, 1993; Kuhse, 1997; Sevenhuijsen, 2003; Peace, 1998) emphasise that assuming the responsibility to meet the needs of the cared-for is part of accepting the burden of care. Tronto (1993) argues that taking care of someone includes ideas of agency and responsibility. Taraborrelli (1994) suggests that family caregivers who are initially drawn into the caregiving role by feelings of love and gendered rules of filial responsibilities learn to replace the 'lay perspective' with the 'carer perspective' to care. She observes that "one of the more immediate indicators, and manifestations, of a caregiver's 'conversion' involves their attitude towards the use of various services… changes in their orientations towards their activities; their relationships with the person being cared for; and in their conceptualizations of care and caring" (p.33-34). Such conversions form part of adjusting to the role and accepting that care was work with physical and emotional burdens and recognising that the support services provided from outside were part of care and accepting them did not imply abandoning the ill relatives.

The experiences of the caregivers when the patients were not admitted should be understood in view of their immediacy to the illness situation. They considered themselves as knowledgeable in many ways and expected the medical professionals to confirm their judgement of the situation by providing what they considered as appropriate form of treatment. However, the caregivers were aware of their inability to contribute their viewpoint and influence medical decisions concerning hospitalisation of the patients. Their emotions when they could not access hospitalisation included disillusionment which could also affect the care-recipients. These dynamics reflect some of the tension between lay knowledge and professional knowledge and suggest that medical practices in this realm did not consider the experiences of the caregivers, which is also in contradiction with the sentiments of the holistic approach and the claim that home-based care is meant to empower families in dealing with HIV and AIDS. What may be read from the caregivers' encounters was that instead of "taking subjectivity seriously", the health care providers saw "it as an impediment" (Williams and Popay, 1994: 123) to expert knowledge and rationally decided upon responses to the care needs of the chronically ill as determined by planners. Faced with the responsibility to act on behalf of severely ill patients who could hardly communicate their needs to healthcare personnel, the caregivers perceived themselves as an important link in relaying the significance of the symptoms which they experienced and perceived as life-threatening from the lay person's perspective. The perception that caregivers' experiential knowledge was disregarded by those with the expertise and recognised knowledge in health matters casts doubt on the possibility of continuity of care and the goal of home based care as *not* to abdicate the burden of caregiving to the powerless whose exploitation in this respect may be made possible by their emotional attachment to the recipients of home-care.

Another important consequence of the medical encounters was the caregivers' interpretations of the professionals' actions and utterances and their consequences for care. For example, suggesting that there was nothing which could be done was viewed as insensitivity. The traditional health care perspective does not provide explanatory models for incurable illnesses and the medical practice does not usually express uncertainty and poor prognosis. As members of the cultural system, they were conscious of some of the meanings of 'AIDS' prevalent in society. These included returning from 'the Republic' ill, not being admitted to hospital while visibly ill, bodily sores, being cared for at home, coughing persistently and not responding to TB treatment and diarrhoea which made them susceptible to felt stigma. They felt that the patients were rejected and treated inhumanely and concluded that it was because their symptoms were associated with AIDS. Experiences of this nature reinforced felt stigma among the caregivers and the care-recipients and it was common to feel reluctant to return to the hospitals after being rejected; while being outside the hospital with severe symptoms was also a rich metaphor of AIDS-related illness. The negative consequences of stigma as an inhibiting factor for seeking treatment for STIs (Lichtenstein, 2003) and for HIV and AIDS (Stansbury and Sierra, 2004) have been reported. According to the 'resocialized' conceptualisation of stigma which recognizes the significance of structural aspects and power in the process of stigmatisation, power differentials between those with the negatively viewed mark and those without is a critical element (Link, Struening, Rahav, Phelan and Nuttbrock, 1997; Link and Phelan, 2001; Green, Davis, Karshmer, Marsh and Straight, 2005; Castro and Farmer, 2005). The process leads to status loss and the persons whose "differentness" is linked to negative and undesirable attributes experience discrimination which lead to unequal outcomes. Unfortunately, the caregivers' experiences suggest that stigma lingered in these supposedly supportive places. Poindexter (2005:2) has observed that stigma and discrimination are experienced from "sacred domains – family, medicine, and church". Fear of exposure to infection and unwillingness to treat AIDS patients were also reported among the physicians yet they were prepared to treat other highly infectious diseases and deal with equally stressful situations of terminal illness (Yedidia, Barr and Berry, 1993).

This chapter attempted to analyse how the family caregivers experienced the consequences of the policy shift intended to reduce the burden of AIDS-related illness from the hospitals by shifting the care responsibilities to the domestic domain. There are different assumptions about the world of care work and one of the common ones is the division of labour between formal institutions and the home sphere in the care of dependent population categories. To analyse the caregivers' experiences, the circumstances under which they consulted the hospitals and the outcomes of such endeavours were delineated with the intention of illustrating that the caregivers' expectations were often not met. When people did not have information pertaining to the basis for the health professionals' decisions on how the patients' care needs would be met, it was difficult to comprehend the behaviour of the doctors which seemed to contradict the established norms of caring for severely ill members of society. Most importantly, it became apparent that the hospitals did not exhibit the same level of urgency to admit the patients who were critically ill. Consequently, the caregivers had stressful experiences because the form of support they anticipated from the hospitals did not come forth. Although chronic illness and home-based care are by definition outside the realm of medicine and both increase the experiential knowledge of the lay people who manage the illness with minimal medical help, the caregivers' perspectives on the care needs of the patients were ignored during medical encounters.

It was difficult to ensure continuity of care under these circumstances and unlike a few caregivers whose subjective opinion about the situation of the care-recipients usually led to anticipated medical interventions, most caregivers were frustrated by the actions of the insensitive health care workers. The notions of demedicalisation, rationing and holistic approach to health provide some explanations for the caregivers' experiences by providing context to AIDS home-based care and linking it to the larger structural aspects of health care. Although the caregivers retained their agency and persisted to seek hospitalisation when they perceived it necessary, the institutional interest to maintain the costs low meant that the patients would not be admitted even when they were experiencing distressing symptoms while those who were admitted were discharged to home before recovery. The perception that the symptoms also inhibited hospitalisation raised the concern that the messiness of the AIDS disease, one of the reasons it has attracted severe stigma (Powell-Cope and Brown, 1992) and the desire to maintain hospitals orderly and sanitised could jeopardise the care of those whose bodies are "leaky" and contaminating. Poor connections between the homes and hospitals exacerbated stigma and the feelings of being excluded from this form of care.

Walmsley (1998: 7) points out, "[C]are is about people. Whatever policies, structures and financing arrangements are in place, the litmus test of care is how it is experienced by individuals – caregivers and those who are cared for". Also, the concern that "the cost can become a punitive societal trend… used as a rationale to reduce medical services to the poor, withdraw a variety of resources from the sick and disabled, and stigmatise those who are ill" has been discussed in the context of demedicalisation (Lowenberg and Davis, 1994: 587) and it was a reality for those who assumed the responsibility of providing care for people with AIDS-related illness at home under stringent conditions of public spending and within a milieu characterised by a poor ethic of care.

CHAPTER SIX

EXPERIENCES WITH MEDICAL CARE AND EFFICACY OF TREATMENTS

Medicines are important for treating both acute and chronic illnesses. The notion that HIV/AIDS is a chronic disease implies that although it is not curable, the symptoms are treatable and manageable with medicines. Since medicines are integral to the doctor-patient relationship, when people experience severe illness they expect doctors to apply expert knowledge and prescribe effective medicines on the basis of an objective diagnosis. In return, the family members expect the sick to comply with the doctors' prescriptions in order to realise the intended treatment outcomes – either cure or symptom alleviation depending on the prognosis of the illness. Prescription of ARVs would retain this normality in the doctor-patient relationship in the context of HIV/AIDS. In the absence of these therapies ordinariness was maintained when doctors prescribed medicines to treat the opportunistic infections. But medical treatments which did not include ARVs had limited efficacy; the health of the patients continued to deteriorate while on treatment.

In this chapter the caregivers' experiences with the medical prescriptions will be analysed taking into account the fact that the caregivers considered medicines as essential in home care but not all of them knew about the HIV/AIDS condition of the patients. All the care-recipients were not on ARVs but they had varying degrees of medical care. The factors which influenced their perceptions about them were the relevance of diagnosis in accessing medical care, appropriateness of prescriptions, use and efficacy. Firstly, the significance of diagnosis as a basis on which the caregivers helped the care-patients to seek medical treatment will be considered. This will highlight that since the treatment for TB and opportunistic infections due to HIV and AIDS were subsidised by government, it was critical that the caregivers knew about the HIV and AIDS status of the care-recipients because they could negotiate treatment without pay. Access of the patients to medical care was influenced by the economic factors such the households' ability to transfer the patients from home to hospital. In the context of widespread poverty severe illness jeopardised access to health care because debilitation and disability constrained the patients' mobility and led to situations where care occurred without medication. The patients' biophysical conditions such as lost mobility and bouts of diarrhoea which the caregivers perceived as a threat to the patients' dignity and dealt with them privately constricted care options. Secondly, the caregivers' perceptions concerning the importance of medicines in caregiving will be considered in relation to the doubt which was introduced by what they perceived as the doctors' inconsistencies regarding prescribing practices, and how these perceptions sustained the view that diagnosis was incomprehensive or the doctors did not care about the patients. Thirdly, non-compliance with the treatments will be discussed taking into account how this behaviour threatened care and produced varied experiences at different stages of illness.

Lastly, the caregivers' perceptions about the effects of medicines will be analysed by considering both the positive and negative outcomes of the different forms of treatment and the optimism or lack of it experienced in this realm of caregiving. This analysis recognises that care is a process with expectations and that communication about diagnosis and prognosis influenced such expectations. It will be argued that the caregivers' experiences were embedded in the discourse of unavailability of ARVs which was dominant in Lesotho prior to 2004. The period is referred to as "pre-ARVs" because these therapies were not available to the majority of the people who needed them in society and since government could not 'afford' them and provide them through public financing, they were talked about as 'unavailable' even though one church hospital and private doctors prescribed them. Therefore, the unavailability discourse manifested in different ways depending on whether medical care was from the Maluti hospital or the government institution where ARVs were not available.

Diagnosis and perceived appropriateness of prescriptions

The caregivers spent a long time searching for a medical diagnosis which would solve the symptoms puzzle and lead to identification of treatment. Their expectations about the role of the doctors in making diagnosis which should ideally lead to prescription were resolute. Once diagnosis was made, caregiving experiences tended to be influenced by whether the patients could obtain medication. The doctors maintained the traditional role of prescribing medicines even when more was expected. Some caregiver stated:

> *They gave her tablets and we came back (Mother3).*

> *She was never hospitalised…They gave her tablets again (Mother2)*

> *They just gave him tablets which did not help him because as he was taking them he continued to complain about these pains (Father2)*

> *I think when you take someone to the doctor she must be given everything that the doctor thinks will help the patient, but we are told to buy them separately, that's what I did not understand. You see they told us everything about them – that they were going to make her better because she would not be very ill all the time, but afterwards we were told that they have to be bought every month for that price…then I said what is the use? …why would someone go to hospital and instead of being given the necessary medication she is told she has to buy these other ones separately? (Sibling)*

Disillusionment with treatment was inevitable when the caregivers were aware from the beginning that the patients were not prescribed the most effective medicines. Those who knew about the HIV and AIDS diagnosis realised that the patients were not prescribed the medicines which would ameliorate the illness. The doctors assessed the ability of the households to sustain the long-term treatment from the financial point of view and it was on the basis of the family members' economic status that the patients were put on a non-ARVs treatment. Consequently, knowing that the patients were not receiving optimal medical care was disturbing. A caregiver who questioned the choice of money over life and what she considered as changed values of a hospital which she previously trusted indicated her confusion:

> *They told us about these other tablets and they said it was necessary that she takes them because they would make her much better, but they are very expensive. They said they cost a lot of money, close to R300… We would have to pay for those ones separately but we could not so she is not taking them. We were called and asked if we would be able to pay for those tablets every month … how could we? It's difficult to get the food that we need here because now it is like my mother is feeding two families; those at home and the two of us here, we could not… I felt pain sinking in my heart; I realized that we were poor. I don't care that we don't have a lot of money but my parents would always take us to the doctors right here at the hospital when we were ill, and we got better and after some time we are fine. I was hurt because I was saying so there are medicines! I wished we could afford them, but I immediately told myself that it was no use worrying about these medicines which I don't even know. I was hurt because I was saying this person goes to hospital but the hospital does not give her the medication which they say they know is needed to help her, but she keeps on going there, given something else and not what will really help her. So every time when she is ill, I think about this...what's the use? (Sibling)*

Certainly, these experiences were different to when the caregivers had accepted the explanation that medical treatment for the HIV and AIDS disease was not available or unsuspectingly believed that the doctors prescribed the best possible medicines. For example, those who accepted the 'no treatment' explanation focused on the present and drew comfort from other factors including their spirituality, traditional medicine and the fact that there were encouraging conditions about the patients which suggested a hopeful future. They hoped that the care-recipients would persevere until the time when ARVs would be 'available'.

> *After doing blood tests the counsellor explained to me, she told me and said, your patient has a problem. I did not understand so I asked her, what kind of a problem? She said she has this 'infection disease', meaning HIV/AIDS…We were given TB medication and other medicines and multivitamins, I obtained herbs for her to treat the wounds that she had developed on her 'private parts' which were not healing. With those herbs the wounds became better. When she told me this I felt confused. I looked at her and I think she could read my confusion. She told me that I should not be afraid because many people were facing the same problem, and that I'm not alone (Aunt)*
>
> *Our general approach is to give him the best that we can, sometimes even more than our own children because we realize that he has special needs which should be met if he were to survive this disease. We hope that he lives longer and we trust in God that He will help him survive this disease, he will grow up and may be one day there will be effective cure for HIV/AIDS. May be it will happen. Different things give us hope about him. One time my sister took him to a [private clinic] when he was ill and she told the doctor about his condition. The doctor could not stop marvelling this boy saying that he has really lived for long if he had reached six years already. It is such things that give me courage (Uncle1).*
>
> *I personally had hope that may be he would survive…I wanted him to be courageous because I still had this hope that he was young and if he could be stronger he would recover his health and live well again (Spouse2)*

The caregivers' experiences with medication could also be influenced by whether or not they perceived the medicines to be appropriate for the known diagnosis and observed symptoms. They were concerned that the doctors misdiagnosed the symptoms and therefore prescribed ineffective medicines. One participant indicated that a care-recipient whose death she perceived as unjustifiable wasted time on a wrong treatment because she was initially misdiagnosed with stomach ulcers. She was encouraged when TB was eventually detected because she doubted the previous diagnosis; however, the care-recipient was later given 'a useless prescription' which reversed the progress which they had made over three months. Although the drugs were appropriate for TB, she was concerned about the inadequate TB dose which a doctor prescribed against her objection. She lamented the negligence of a doctor who ignored her discontent with the prescription saying:

> *In the third month they gave her an envelope of tablets labelled 1½ a day. She had already recovered and for these two months she was doing very well. It was this packet of red tablets which directed her to take 1½ tablet a day which brought her down again…I showed the tablets to (a nurse) and said to her: 'I have been involved in community-based care for TB patients and I know very well what kind of medication they get and how they take it, I have never seen any time this kind of prescription… This one I can see already that she is going to die but it doesn't matter'. Thereafter she could not breathe properly…At that time I was stuck because the tablets were provided by a doctor who is said to have attended school for years and nurses who have been trained for years, I did not know what to say to whom. We just waited hopelessly until she died (Mother-in-law).*

Access to medical treatment

Since all the care-recipients were symptomatic it was imperative that they were on medication, all the time. The caregivers' responsibilities in ensuring that the care-recipients had medicine at home involved helping them to attend regular check-ups at the hospitals and obtaining medication. Despite the virtually similar medical circumstances which led to the care-recipients being in home-care, the caregivers had different experiences about access to medical treatment. This situation basically underlined the significance of the information the caregivers had about diagnosis. The help-seeking behaviour of the caregivers and its consequences for caregiving differed according to what may be referred to as the 'operational diagnoses', that is, the diagnosis which formed the basis for seeking medical treatment.

Forms of medical care and access

The caregivers who knew that the care-recipients were HIV and AIDS positive could seek medical treatment for the various symptoms including TB. For example, unlike those who were on TB treatment only, the caregivers who identified the care-recipients as HIV/AIDS patients indicated that they enjoyed access to medical care for various symptoms for free. One such caregiver said:

> *He's not on antiretroviral drugs. What I realize is that they treat the complaint that we present every time when we bring him because he is affected by different illnesses. Sometimes he has acute respiratory problems with fever and he gets tired. And when he is like that we immediately take him to the hospital. Sometimes he complains about headache, again we take him there and they will treat the headache. Like now, they give him ointments that we apply to his body due to the blisters and these are what we're mainly treating now (Uncle1).*

> *At the hospital they help because they give her some tablets (multivitamin) which they say make her feel stronger and they say they weaken the virus in her blood... they say because they are expensive [ARVs] they cannot be given free like the others that she gets for free... (Sibling)*

In contrast a caregiver who had experienced the diagnosis shifting from HIV/AIDS to TB stated that:

> *When she first became ill, we went from one place to another seeking help. A lot of money was spent. But at the moment it is better because the hospital is taking care of her, she is now the responsibility of government. When she is hospitalized or attends her check-ups we don't pay anything. She only paid once when she had diarrhoea and was hospitalized for one week... And she does not pay for TB treatment and staying in hospital. But if she has other complaints and pains she pays for the medicines (Father1)*

The care-recipients who were diagnosed with TB were almost guaranteed with the necessary medication because they followed a free six-month treatment which entailed attending monthly check-ups, a regular supply of drugs and food parcels from the hospitals.

> *She did not pay at the hospital because of TB (Aunt)*
>
> *He still has his TB tablets and he collects them at the end of every month when the tablets are finished (Father3)*
>
> *We were actually encouraging her to stick to her medicines and we advised her not to wait until they were all finished. She would go when she had five tablets remaining. She would go back, and indeed this was what my child was doing (Mother2)*
>
> *I now realize that she is also encouraged these days and I am not worried about her any more because she now informs me whenever her herbs or her tablets from the hospital are finished, then I'll give her transport money to the hospital to collect the tablets (Father1)*

An elderly mother who was anxious because the family could not raise the consultation fee for her daughter who was in remission stated that things could have been different if the patient had TB:

> *Her tablets are also finished. I wish she could go back to the hospital while she is still like this because I don't want to see her going back to that condition again. But the problem is money. You see if she had tested positive for TB she would just go because TB is treated for free but other problems, you have to pay for their medication... What I wish is for her to see the doctor because I think she cannot afford to live without medication anymore, she needs to have tablets all the time. ...but we have no choice; we cannot afford it (Mother3)*

The care-recipients had differentiated access to medical care depending on whether or not the salient diagnosis known to the caregiver was one for which treatment from the hospitals was free because they negotiated medical care on the basis of such knowledge. The caregivers who cared for known HIV and AIDS patients received free medical support for any medical problems the patients suffered - chest pains, blood-stained sputum, pneumonia, fever, headaches and skin infections such as herpes zoster, inexplicable wounds and rashes. They also received some of the alternative therapies such as vitamins and the *"African Solution"* – a tonic which has the African potato as its main ingredient. Some people believe this tonic improves immunity. One of the caregivers linked improvement in the quality of life of the care-recipient including reduced illness episodes and their severity to the medicine. This meant that although the patients did not receive ARVs, they could access a range of therapies which were intended to alleviate symptoms without incurring personal costs and this only happened following their awareness that the care-recipients were ill from AIDS. This situation was different from the category of caregivers who cared for individuals who were on TB treatment but not identified as HIV and AIDS patients since medication for other recurring symptoms which could also be opportunistic infections were not free. Some patients would not obtain free TB treatment after they were discharged even though the symptoms persisted or they experienced new problems.

However, the category with the least access to medical support, especially in situations where there were serious economic constraints, were the caregivers who cared for patients who were severely ill but were 'diagnosed' with neither TB nor HIV and AIDS. These patients consulted the hospitals to treat the symptoms as they occurred and they received prescriptions for the myriad conditions such as chest pains, pneumonia and excessive water in the lungs, fever, cold back and feet, aching feet, coughing, inexplicable wounds, headaches, ulcers, asthma, STIs and skin infections for which they paid fees. The need to pay for healthcare costs had to be considered when symptoms occurred and it was an inhibiting factor to medical access. As a result there were some caregivers who paradoxically suggested that a TB diagnosis was advantageous while others indicated that their caregiving experiences in terms of medical support by the hospitals changed tremendously following the HIV and AIDS diagnosis.

Table 6.1 below illustrates five types of care-recipients according to the different forms of medical treatment which the patients obtained on the basis of the 'operational diagnoses'. All the regimens did not include antiretroviral drugs but access to the different care packages provided in the hospitals was influenced by diagnosis.

Table 6.1 Typology of care-recipients in home-care and forms of medical treatment available

'Operational diagnosis'	**Other Symptoms**	**Forms of and access to medical care**
Type A: HIV/AIDS		Free treatment for all infections *(Comprehensive)*
Type B: Tuberculosis only	None	Free TB treatment package *(Comprehensive)*
Type C: *HIV/AIDS & TB*	Yes	Free treatment for all symptoms *(Comprehensive)*
Type D: *Tuberculosis & other symptoms*	Yes	Free TB treatment, self-financing of any *symptoms* other symptoms *(Not comprehensive)*
Type E: Other symptoms: Not TB, not HIV/AIDS	Yes	Self-financing *(Least access)*

Perceived importance of medicine in caregiving

The caregivers considered medication integral to caregiving and tried hard to ensure that prescriptions were followed. They believed that the medicines brought a difference in caregiving. This aspect was illustrated through the various efforts which were meant to facilitate the intake of medication. They expected the care-recipients to play their part and act responsibly. Some caregivers said:

> *...there were days when I could not go anywhere during the time when she was very ill; I stayed at home because I wanted her to take medication because at that time she could not even reach for a mug of water placed next to her; she was very bad... I was speaking strongly to her... because I did not want her to skip ... medicines. When I left I would place food and the tablets next to her and go (Aunt)*

> *I told you that she has become very responsible these days, I don't even have to supervise her closely, well I can remind her but I know she does not cheat (Father1)*

> *That's why I find it necessary that even when he is not living with me here I go to his place on a daily basis to ensure that he has taken his medication. I just want to ensure that he is taking his medication (Sister- in- law1)*

Caregiving without medication

The caregivers were concerned about medical treatment being disrupted, and became anxious when medication finished before the check-up dates or did not have the means to take the patients to hospital. A caregiver described her desperate attempts to ensure that the treatment was not disrupted. She said:

> *I was used to a situation whereby we would go to collect her monthly prescription even before her tablets could get finished. But with this 1½ dose when I went they were already finished but I came back empty handed. I was forced to go to one family that I knew had a TB patient to ask for TB tablets. I asked for six red tablets which I hoped would last for three days. I didn't know what I was doing, it was because I was anxious that she would spend a day without medication but I did not know what would happen after these three days. I didn't know where I would go. They got finished after these three days and she spent two days without medication and on the third day I went back to the hospital. But this time they agreed to give me the tablets. You see she had already spent these days without proper medication. I resumed the treatment but there was no use. What remains a puzzle is that this last packet which they gave me, it was saying two tablets once a day! I still don't understand what led to the one-and-half dosage (Mother-in-law)*

While they waited for the care-recipients to resume treatment, they helplessly watched the symptoms worsening. The caregivers blamed poverty for their delay to seek health care. For example, a caregiver waited while the symptoms progressed before the patient could return to hospital even though she was convinced consultation was necessary. She said:

> *...this thing was not gone, it was just hiding, she was not cured... her father got R10 from his friends and I took her to the hospital...You see as you are now, you feel fit but there could be something that is eating you slowly and by the time you know it will be too late. If the medicine is taken in time, one, two, three you would see change. But these ones (tablets) did not do that because the damage had already been done. And this is because we took so long before we could go to doctors and this was because we are poor...there is no cent in this house. And by the time you get money the disease has "climbed the steps". By the time you have money it is up and you are now going to battle with a more serious problem. It would be better to go to doctor immediately when you feel pain. This is not what happened with this child (Mother2)*

An elderly caregiver of a care-recipient who died during fieldwork indicated that she helplessly watched the care-recipient, who had been without medication for more than four months despite the severe pain and diarrhoea, deteriorate. The patient became bedridden and this situation together with the persistent diarrhoea made it impossible to use public transport. She said:

> *There is no medication at all. All the medication got finished because she has now stopped seeing the private doctor who used to come here. Medication is finished because at the moment, she cannot get to the health centre or hospital, she cannot get to the bus stop, we are just watching her. I cannot collect any medication, because she cannot get to the place where she can be examined and doctors will not just give medication. We are just watching her; there is no medication that she is taking. It is painful because she says her whole body is aching all over and anybody can see that she is suffering (Mother1)*

Another caregiver who was shocked by the patient's abrupt relapse said:

> *This time I have lost hope with her. I can see that she is battling but I don't think she will be better this time because we don't even have any medicine to give her, we are just watching her because we cannot get her to hospital. But if she could go to hospital maybe doctors would do something but my mother keeps saying we should just wait maybe the next day she will be better. I think she has lost hope too. But I understand mother because we cannot carry her to hospital now since she cannot even stand or sit. There is no way we can get her there. We need a car to take her there but my mother does not have money to hire a car. She also has diarrhoea and I wanted her to recover and she has now stopped but it is still worrying. Maybe she will be better; I don't know (Sibling).*

A caregiver of a patient who died stated:

> *I wanted her to go back to hospital even though I did not intend to leave her at the hospital; I simply wanted her to see a doctor and come back home. But she could not walk to the bus stop (about ½ km from home). I had to just sit and watch her. Although she had recovered remarkably she suddenly became weak again when she was given this useless prescription. She could not walk herself because her feet would not carry her to the bus stop (Mother-in-law)*

But the health care providers were also blamed for the mishaps concerning disruption of treatment during caregiving. A caregiver who blamed a medical doctor for the death of a relative said:

> *I thought that these people have been trained for ages there is no way I am going to interfere with their work and what they prescribed. I just said, well come what may come, I was expecting anything. What this told me was that they wanted her to die. When I showed a nurse the tablets she said that they [tablets] were supposed to be enough for 2 weeks and not thirty days. I could not understand, I became confused because I knew that there was nothing like 1½ tablets for TB, there is nothing like that. The tablets got finished after two weeks... M died, well, it has happened, but it could have been prevented (Mother-in-law)*

Anyhow, the caregivers believed that medication could bring about change. Therefore, providing care to patients who did not have adequate medication was one of the distressing situations in caregiving because it meant watching them helplessly while they suffered. The factors responsible for the situation were physiological, social and medical. Similarly, the behaviour of the care-recipients affected caregiving experiences profoundly.

Perceived consequences of disrupted medical treatment

Ensuring that the care-recipients used the medicines involved two aspects: availability of medicines at home and helping the care-recipients comply with the doctors' instructions. But medical treatment was sometimes disrupted due to a variety of factors including lack of money for consultation and obtaining suitable transport to hospitals when the patients were severely ill, under-prescription whereby medication did not last the intended period, and finally, the care-recipients not complying. Notwithstanding the circumstances under which it happened, disruption of medical treatment was a painful experience because it tended to be viewed as the reason for recurrence of illness or failure to recover while in some situations it was the prelude to death.

Severity of symptoms and economic influences on access

Basically, access to medication meant reaching the hospitals for consultations, obtaining diagnosis and attending regular check-ups. Most caregivers supported or accompanied the care-recipients to reach healthcare facilities without difficulty. When families did not have money for privately arranged transport to take the patients who could not walk to the bus-stops to hospitals, the patients could not have medical attention and in some instances they went without the essential medication such as painkillers and treatments for skin infections. It was distressing to see the patients persevering as they travelled to and from hospitals for treatment. One caregiver described such distressful times in the context of early discharge and possible side-effects of the treatment:

> *There was a time when she was discharged and she was still very ill and they instructed her to go to hospital everyday. You can just imagine. I did not understand them. I could not understand how they would discharge a patient who was so ill yet they still wanted to see her everyday…That was hell to me, because she would not walk to the hospital alone. She was always tired. She was vomiting all the time… I would accompany her everyday, she did not eat well, and you could see that she was exhausted, very weak. I finally realized that this person was actually ill again, every time when we returned from hospital you would realize serious problems of someone who is sicker than when she went to hospital in the morning. I don't know what they were doing to her; I don't know what they were giving her, because she saw a doctor or nurse everyday. It was a problem everyday when I had to persuade her to go to hospital again and I understood because she was exhausted. I sent a message home to let my mother know. I must confess, I called her because I feared something unpleasant could happen… (Sibling)*

In most cases the caregivers incurred higher transport costs to take the patients who could not reach the normal bus-stops to hospitals and it was difficult for poor families to raise this money. For example, a caregiver who had to wait for days before a severely ill patient could initiate treatment said:

> *I don't want to hide anything from you: we are struggling in my family but also we are not a family with solidarity. When she arrived I went out to the person who usually gives me piece-jobs, she gave me some money to take her to hospital. I was going to work afterwards. That's how I survive with these kids. That Tuesday we went to hospital but we couldn't complete the examinations... we were not able to make blood tests... We were told to return the following day... We could not go on Wednesday so I asked them to allocate me for Thursday. This was because I did not have money; I had to go for a piece-job so that we could get money for transport. Since she couldn't walk I had to take a 'four-plus-one' (taxi) off the line to take her to the hospital, and that costs R20.00 (Aunt)*

Another caregiver who had to delay diagnosis which could have lead to a different form of intervention indicated that her experiences were exacerbated by malfunctioning equipment at the hospital.

> *She was taken to X-ray but they said it was not working and we did not have money to take her to Mapoteng so that she could have the X-ray. We waited. They said that there was no water to run X-ray. So during that week which I could have taken her to Mapoteng, she died, but already she could not walk and we would need a car to get her there (Mother2)*

Experiences with non-adherence to treatment

The caregivers upheld the medical value concerning compliance with medication. One of the situations they found distressing was when the care-recipients disregarded the instructions. Their experiences also depended on the stage of illness when it was observed and their perceptions about the motives of the care-recipient. For example, non-compliance at the time when there were no obvious symptoms which could hinder ingestion of medication was regarded as negligence and noncommittal attitude on the part of the cared-for. A caregiver said:

> *At this time it was very annoying because she would not take her medication. I was worried when she refused to take medicines because I was saying to her I don't think the hospital brought her home because she is cured, she was not even better in any way... So I wanted her to take her medicines as directed (Sibling)*

While persuading the patients was mainly adopted, deception or coercion were also used even though the caregivers disliked doing it. One caregiver stated:

> *It was not nice to me, I did not want to force him but I wanted to help him, I wanted him to get better. I did not negotiate or warn him that I was bringing medication, otherwise he made my work difficult because he just refused to take them and there was nothing I could do, but to me it was so painful because I saw this person just throwing away his chance to have a life, but what could I do? I would make a solution of his tablets and medicines in water and persuade him to drink (Spouse2)*

The care-recipients could also be blamed for being insensitive to the needs of the caregivers. A caregiver observed non-adherence to medication quite early in the caregiving role and her emotions shifted from worry to anger when she found out that the care-recipient had been avoiding medicine:

> *At one stage she was not even taking her medication, I would give her food and tablets, then leave the house for piece jobs, you know what she did, she would throw the tablets into the bucket which I always leave next to her so that she can throw up or urinate or whatever when I am not at home. I wouldn't realize this because of the colour of urine. Later when I saw that the colour of her urine in the bucket was red, I was shocked because I did not know anything about an AIDS patient so I thought that she was urinating blood. I could not keep quiet; I talked about this to a friend who used to visit her when I was not around. You know what she told me? That (patient) was throwing her TB tablets into that bucket everyday, so she was not taking her tablets. I got mad. I told her that she was causing me unnecessary trouble and that she had troubled me for a long time and that it was enough. I told her that I have tried to nurse her but I am not getting any indication that she appreciates what I am doing… I said: I'm not gaining anything from you, I struggle to get the money which I use to take you to the hospital, when you have medication you through it into urine, how do you expect to recover? I felt that she did not care to live but was making me suffer and worry about her while she was not concerned… But she is also discouraging, if you go to her place you'll find that there is a heap of tablets and medicines, every time when she is ill she takes medication for sometime when she feels better she stops. This is what is discouraging… I expected her to be responsible (Aunt)*

However, similar behaviour was experienced with grief if it was interpreted to signal distress on the part of the care-recipients. For instance, nausea was one of the symptoms which hindered the intake of medication. Some caregivers expressed pity saying:

> *…She said they had a horrible smell, I don't know and she was vomiting all the time. I tried to break the tablets into powder so that she could swallow them easily, but she would immediately vomit and remain nauseous and would not eat I don't know if she could not swallow them because she was vomiting or if they caused her nausea. That was very distressing because she could not eat and I wanted her to gain weight and be stronger again. She was very ill at the time, even her being discharged was just done because doctors are doctors… (Sibling)*
>
> *It was difficult because even tablets she could not swallow them… Even though I was hopeful because she could still eat well and take medicines, when she suddenly came down it was so many problems at once, I was just puzzled and did not know what was happening…(Sister-in-law3)*

A father who felt helpless because he also disliked tablets indicated that he felt inadequate when he had to encourage the care-recipient to take TB drugs. He said:

> *There was a time when she was dodging medication. She was complaining that the check-ups and tablets were too many. At that time I felt bad because I could not help her much by way of saying,*

> *no take your medication because I don't like tablets too...they irritate me...I can't swallow them (Father1)*

Non-compliance was also experienced with sadness when it signalled surrender to death by the care-recipients. Usually, it was saddening because it ushered in fear that death could be imminent. One caregiver said:

> *I try to give her the painkillers that she gets from the hospital but it does not help because sometimes she cannot even take her medication. I am suffering too...Sometimes I become scared, I fear that something terrible might happen...I don't know but she scares me sometimes. I worry that if God the Father decides to remember His child while I am here alone, what am I going to do? It feels better when my mother is here too (Sibling)*

Another indicated that the behaviour depressed her because the care-recipient gave up too soon while she was still hopeful, especially because they received tremendous medical support from the hospital following their HIV diagnosis. The nurses visited regularly and brought the patient some medicines. She said:

> *By the time he became bedridden he had long stopped taking his medication. I believe that if he had continued to take his medication, his check-up day could have found him still alive... It is a very painful experience because as a caregiver you are always hoping for the best, that if he continues to take his medication he will become better. It hurts me emotionally because I saw this person refusing medication though I personally had hope that may be he would survive. He did not take it even when I tried to encourage him saying that probably these medicines would help him. At times I even tried to lighten things for him by saying that probably it was not even HIV... and if he kept trying to take medication he would recover. I did not know what I should do to make him feel better. I was trying to encourage him but he defeated me...I had to force him; he said he did not see any use because he was not going to live anyway...Sometimes he would just see me with a spoon of medicine, and I did not negotiate...When he became aware he refused completely. It made me sad... I saw him abandoning me in the middle of a battle which I had promised him that we were going to fight* ***'it'*** *together. I was disappointed (Spouse2).*

It was not easy for caregivers when the cared-for lost hope. A mother said this about the distress she suffered when the patient lost hope even though she later recovered:

> *It was tough and very difficult. I would not want to go through the same experience again and I am glad that she has recovered this much. I was not expecting anything of that nature at all, so it was tough and I was burdened I don't want to lie, but I had to carry on. You know when you are dealing with someone who has lost hope. She did not even want to go to the hospital or anything she only went when other people pleaded with her because she had lost hope and had given up. She was not missing life at all (Mother3).*

Another stated:

> *...but she does not like the tablets of late, this is becoming a problem for me; she says the tablets make her feel sick. I don't know because these days I can see, we were even talking about it with my*

> *aunt, that it seems her head is not working well these days, she even forgets these kids' names (Daughter)*

Some care-recipients actually verbalized their hopelessness, and refused to continue taking medication. In general, the behaviour made the caregivers feel desperate. A mother who was still hopeful became distressed when the care-recipient announced her decision to discontinue all the measures of treatment including consulting the doctor. She stated that:

> *At that time I was very troubled; she had started refusing to take the tablets. She refused to take tablets, and I would force her but, no she refused to take them. This was painful because I wanted her to get better and I had not lost hope yet but I could see that she was losing her hope... At that time I was very troubled... (Mother2)*

Experiences with the effects of medicines on the symptoms

The caregivers were confronted with perplexing situations with regard to the outcomes of medical treatment. Irrespective of whether or not they knew about the HIV and AIDS status of the care-recipients, the caregivers expected the medicines which the doctors prescribed to work. Others appreciated the fact that HIV and AIDS could not be cured but hoped that the medicines could ameliorate the symptoms. But more challenges were encountered when there was limited understanding about the context of the symptoms.

Positive experiences

Some caregivers observed significant positive changes when they administered specific medicines including traditional herbs. These changes were reduction in illness episodes and severity of symptoms. The most important consequences of these particular changes were that hospital consultations ceased to be erratic; they only went for regular check-ups, and anxiety about death subsided.

> *It has changed a lot because since the beginning of the year, he has not been severely ill. His condition has really improved, there are no acute attacks...You know before he used this medicine, he would take a month, and then he would not finish a month before he had a serious attack. Sometimes it would happen twice a month and when it happened he would be really bad so much that I would even think that he was going to die. He would later recover after some days but look very exhausted. But at present I think he has become better... At the moment this feeling that he could die at any time has subsided because he looks much better after he was prescribed these medicines. He still becomes sick sometimes but not as severe as it used to be. (Uncle1)*

> *When I was caring for her I was convinced that I was caring for someone who was going to die anytime. Then all of a sudden she became better and she could walk again, that's when she started being troublesome. I was caring for someone who was heading for the grave; I was not counting her among those who will still be breathing today... When you see her now you see a healthy person, she was not like this when she got here; many people still can't believe their eyes... (Aunt)*

The caregiver who had recently experienced a life threatening episode of illness which led to lengthy hospitalization was concerned about the new symptoms but found them relatively mild and controllable with alternative treatments said:

> *She is much better even though when she came back from the hospital after these two weeks she developed these rashes. She was scratching herself and I tried to give her some herbal medicines in addition to the ointment that they had given her at the hospital. I was hoping to force these rashes to come out of the skin. It really doesn't matter even if it can cause her blemishes on the body as long as she is alive. What I want is to take it out of her system. I can see that they are beginning to subside even though I don't expect them to disappear immediately (Father1)*

In addition, improved physical appearance and weight gain were also perceived positively because they reduced both emotional stress and physical burden in caregiving. A caregiver who had experienced a situation whereby the healthcare workers declared the patient to be 'without life', said:

> *But as you can see she is much better because at that time she had lost so much weight. I'm telling you all that was left was the skin and bones only... I wish that doctor at TY could see her because the nurse here was so surprised when she saw her last time when she had gone for check-ups. She actually said it again that she did not believe that she would see her so healthy. That is why I say that God has pardoned us with her life. You know she has recovered from these many things and she is much better now even though she has once again started coughing but it is not as bad as when she arrived here... At the hospital they gave her medication, tablets and something to apply on the wounds and she has recovered. And that 'thing' which she was so worried that 'it' was finished is now 'repaired' [*as she says this she laughs a lot and she is joined by the patient who says: *'yes, but you too saw 'it' and who would think 'it' would recover'. It was in a very bad condition] (Mother3)*

A caregiver who had similar experiences for a while said:

> *...she got better and was able to get out of bed and was somehow independent again. She actually became much better; she was well for some time. But she became very, very ill again and my mother and I would take her to the hospital all the time, travelling from home to Maluti... And I can see that medicine works because she is in a good state now (Sibling)*

Another one who observed positive changes said:

> *I did everything for her and there was a time when she really gained weight and one day I said to her, is this oedema or you are gaining flesh? I then pressed her thigh hard with my finger to see the effect but I realized that indeed she had gained weight. That's why I don't understand why she was*

> *given this low dose. Anyway she is dead. But I am bitter because I feel I was robbed of her life, she could still be alive bringing up her children (Mother-in-law)*

Such promising moments were also experienced spiritually,

> *I realize that God has shown His grace and he is up and I am praying to God that please Christ have mercy on him, have mercy on me with this one child that I'm left with (Father2).*

These caregivers were hopeful about their caregiving situation because they either observed changes or received positive feedback from others about the condition of the care-recipients. Some actually interpreted the changes to suggest cure because they had strong faith in some of the drugs which were known to be effective for the diagnosed diseases especially TB and symptoms such as diarrhoea. But this does not mean that such positive signs lasted long or happened without stress.

Negative experiences

Non-responsiveness to medication

Other caregiving experiences which were equally confusing included lack of improvement despite the patients' compliance with the prescribed treatment. The mystery of a TB which did not respond to treatment was a dominant theme and this situation bewildered the caregivers. It introduced doubts about diagnosis especially because in some instances the doctors had initially insisted that they 'could not see what was causing the illnesses' but later diagnosed TB.

> *It is now four months. But there is still no change. This is the thing that I don't understand. Do you see me now? Can you believe that I was also on TB treatment when he was also getting his medicines? But I am well, now. I can do so many things which he cannot do. He is taking medication but I don't see change, especially the pain in the chest and the feet, he still complains a lot… (Father3)*

This was because TB was known to be curable and some of the caregivers had experiential and media based knowledge about the disease.

> *I don't know the disease that is troubling this child. He is still on his TB treatment but I don't see him improving. May be it's me; I want to wake up and see him better, may be but I don't like it when someone is taking tablets everyday, but you can't say you see change... It is becoming common among our young people, they go to the hospital there, they are treated TB and they don't get better,*

> *but very old men go there and when they are discharged they are cured. I don't understand the diseases of today (Uncle2)*

A caregiver who expressed pessimism about the patient's situation indicated:

> *But there is nothing that can be done because there is no turning back we are just watching things progressing, everything cannot go back now because once a disease has entered your body, ah! These days you just have to accept because the medicines are not working. I had thought that by now he would be better because as I tell you all these other people who I advised to go to Maluti are up and about and here he is. Now I don't know but it is still my wish that he gets better although it really hits me when I see him unable to do a thing for himself (Sister-in-law1).*

Poor response to medication was observed with specific conditions too. A caregiver said:

> *I don't think those tablets helped stop diarrhoea because she continued to run for several days. She took the tablets for a week but no change (Mother3)*

> *He would cry because of the pain and sometimes he did not even like to take these tablets. From the beginning he did not give me hope at all, I tried everything but we failed because at this time I had run out of money because all the money that I had saved attended to their mother's health. And I was depending on the hospital. So I was waiting to take him back for check up so that they would test his chest but he died. He was in pain and I was doing everything to help him and his mother. It was difficult but I did my best (Father2)*

Another caregiver indicated that it was painful for him to see that the traditional herbal medicines which he used to treat other patients with similar symptoms could work with them yet he could not cure his own child. Describing this irony he said:

> *You see, because I am a traditional doctor and I cure many people who come here, I always feel a terrible pain when I see this child suffering. Let's say someone very ill comes here and I treat him and they get cured, and I have this child who is very ill. These people come here and very soon they are cured and they leave. But I have this patient in my own house. That thing affects me badly. I always ask myself questions: what is it that I could have done wrong? It is true that sometimes their ailments are different but I generally know that this is how I treat a particular condition. This hurts me, it is painful, do you understand? You wish that this child in your own family could be cured faster and effectively. There is a saying in Sesotho that* **'Moreko ha o irekolle'** *[meaning that if there is something that got into your eye you need someone to help you take it out]. That's why I have gone out of my house to consult other traditional healers… (Father1)*

Usually, subsequent episodes of illness tended to be more severe than the previous ones, and indeed in some instances calm periods were soon followed by death. One caregiver insistently blamed a doctor for prescribing a wrong dose for the patient. This was because she perceived the care-recipient to have recovered tremendously after the diagnosis was reviewed. She indignantly said:

> *I was convinced that God had 'coughed her up'; He was not taking her. I'm saying she had already resumed collecting her food from the hospital, to show that she was much better. You understand that I went there to show them that the tablets which they provided were not enough for the month but they insisted that they were a prescribed amount for one month, and I came out crying (Mother-in-law).*

New symptoms while on medication

There were occasions when the caregivers were aware that the caregivers experienced new conditions which they attributed to the administered medicines. The caregivers who believed that the prescribed medication worsened the situation, said:

> *It is true that after some days, the diarrhoea subsided but then another problem emerged. She stopped going to toilet completely (constipated). I had never seen anything like that. She spent two weeks not going to toilet. You could see that the urge was there but the 'thing' could not come out and she was panting due to pain. She could not sleep, she was turning around in this house and you would think she was in labour. She was breathing with difficulty and screaming with pain. We did not know what to do and she was sweating. I advised her to remain standing and to walk around because she said she could not squad due to pain. I was also panicking but I said just remain standing may be the pressure will push it out... We waited patiently but in vain for the whole night. The problem was that she did not want me to see because I was even thinking that I could take it out using my hands or anything that could help us, even an old spoon. But she refused; she became very wild so I stopped. She began to cry and I pitied her. I felt pain because I could see this child was suffering; sweat was pouring out (Mother3)*

Another stated:

> *It became clear that the actual problem was in the chest, it is just that we took long to realise it. And the tablets did not work. Actually when she took them she became worse; she would be more agitated with pain...Then we would take her to hospital thinking that they would review treatment. They then gave her some tiny tablets; we thought they would reduce pain, but no. We then just watched helplessly, the tablets were not strong but the disease was gaining strength. Whenever we had a R10 we would take her to the dispensary and they would change her tablets and we would think that probably this time they would work, and she would be better, but no, they made her worse. The pain became persistent... there was no use; that was when my child died... (Mother2)*

Relapse

Unfortunately, it was equally possible for the care-recipients to become hopelessly ill after being perceived well for some time and others died at the time when the caregivers were hopeful about the future. Consequently relapse or emergence of new conditions following what was perceived as improvement were devastating and rendered the search for the meaning of the illness futile because the circumstances for relapse were inexplicable.

It was rare to be sceptical when temporary improvements were realized because this was the main aspiration in caregiving. But a caregiver who could not be convinced that the patient was cured even though the doctors had recently given her a clean bill of health said:

> *Thereafter it became better. She was even able to go on her own to the hospital to get her tablets…she was discharged from treatment, however, I was doubtful and I said to her: could this thing be really cured? Could it not be that it has only subsided. The way I see you, you cannot be cured; this thing just lay low, hiding. It didn't take long before she started to cough again; before two weeks lapsed, she started to cough I took her to the dispensary again… She kept on going to the hospital and we would think that she is better but after a few days she would just become ill again (Mother2).*

A feeling of loss and helplessness was particularly experienced if the patient was still on medication and there was no reason to doubt their adherence. As the following narratives illustrate, these were some of the puzzling and discouraging moments:

> *Yes, that time I had really lost hope. At that time we took him to Maluti hospital and he stayed there for a very long time, about a month because he needed to recover. Then we realized that this disease of his is getting worse even though he is taking medication so faithfully, I mean with my help and support. (Sister-in-law1)*
>
> *She was later discharged and she went home and she was taking her medication all the time. All of a sudden she started complaining about headache, this headache denies her rest because she becomes mentally disturbed. She was taken to the hospital again… (Sibling)*
>
> *We have had a tough time here. Remember how this person of mine was fine last time when you were here? You can't believe that she has been to hospital already. I just don't know what happened this time around… She's quite weak I just don't know what happened. She is lying in the sun because it is extremely cold indoors… It was in the afternoon, I came back home and found her lying down and coughing a lot. I don't know what triggered this. She still had her medication so I told her we would wait maybe it would improve. On Friday she did not seem bad but Saturday! She was really bad. She could not breathe at all. Now I don't know what could have happened, this time it just sneaked, I really don't know what kind of a battle we are fighting, this one which does not retreat. You know I still don't understand because she was still taking her TB tablets… (Father1)*

The caregiving experiences in the realm of medical care were dominated more by psychological and instrumental challenges than by physical activities. This was understandable considering that medications were considered crucial. The caregivers were concerned with ensuring access to medical treatment and proper utilization of the medications because they linked medicines to well-being. The support which they obtained from the hospitals in this regard significantly alleviated their anxiety while lack of such support generated overwhelming stress. Diagnosis played a significant part in influencing the form of regimens the hospitals made available to the care-recipients.

One major source of the differences in caregiving experiences was the entitlements of the care-recipients based on the diagnosis. The caregivers realised that their caregiving situations changed positively when they had information pertaining to HIV and AIDS and TB diagnosis because the hospitals supported them differently. These were different from the experiences of the caregivers who sought medical care for other illnesses which could also be opportunistic infections caused by the decline in the immune system but did not have information regarding HIV and AIDS diagnosis. Such care situations produced formidable stress which could be attributed to poor connectivity of the patients and the caregivers to the hospitals. Also, the inability of the caregivers to contextualize the disappointing outcomes of treatment due to insufficient information about diagnosis and prognosis of the illness was constraining. Inability to access medical care due to severity of illness and lack of household income was experienced emotionally because it eroded hope in caregiving. Finally, the caregivers were the custodians of the medical interest and ensured compliance with medication at home. However, the behaviour of the care-recipients and the extent to which the hospitals complemented home-based care through medicines produced different experiences at different stages of caregiving.

Discussion

At the core of the caregivers' experiences with medical treatment was their strong belief that medicine was vital in caregiving. Although there were different degrees of optimism about the expected outcomes of medicines, these substances were generally expected to ameliorate the symptoms. This understanding created expectations about the role of the doctors and the cared-for as well as defining the role of a caregiver. These expectations resembled the Parsonian sick role even though the expected outcomes could be modified in the light of available information concerning the HIV and AIDS diagnosis. Even when HIV and AIDS were acknowledged though, some of the caregivers' coping mechanism was to remain hopeful about the future possible medical developments which could lead to availability of appropriate treatment. Consequently, they hoped that the care-recipients could persevere. In this way, caregiving in this realm mainly comprised emotional work which was meant to maintain mutual optimism (Thomas, Morris and Harman, 2002) and the cared-for were expected to contribute to this goal. The analysis shows the value of conceptualizing of caregiving using the construct of caregiver burden to understand the difficulties encountered by caregivers which recognizes the physical and emotional dimensions of caregiving (Pakenham, Dadds and Terry, 1993). The caregivers' endeavours were meant to alleviate the care-recipients' suffering which also affected them emotionally and they considered obtaining modern medicine and using it as part of maintaining hope and bringing the situation under control.

There were gradations of access to medical care on the basis of diagnosis and ability to reach the hospitals whenever perceived necessary. Specifically, in care situations where the care-recipients were known to be diagnosed with HIV and AIDS and/or TB, the caregivers reported an almost guaranteed access to the essential treatments available in the hospitals. Free treatment and nutritional support for TB and HIV and AIDS patients as part of the societal response to these two chronic diseases which have a tendency of co-infection in African communities (Gwyther and Marston, 2003; van Dyk, 2001) enhanced medical access and contributed to relatively consistent availability and utilization of medical treatment within the home sphere. Interestingly, the caregivers reported positive change in caregiving following the HIV and AIDS and TB diagnosis of the care-recipients. They recognized the advantages of this situation while also noting that diagnosis was a turning point or a critical difference in their experiences. This was due to their recognition that institutional support towards home-care increased subsequent to diagnosis of HIV/AIDS/TB. The significance of the support by health care professionals to family caregivers of chronically ill relatives has been noted in various contexts such as mental illness (Magliano, Fiorillo, De Rosa et al, 2005) and cancer (Blanchard, Ruckdeschel and Albrecht, 1996; Thomas, Morris and Harman, 2002). Therefore, it was inevitable that the caregivers who were satisfied with the support from the hospitals would experience positive changes due of the stability and sense of security provided by the assurance they had with regard to accessing medical treatment. Access to medical care is identified as "a vital component of quality AIDS care" (Dworzanowski, 2002: 422). In the context of home-based care, accessibility of medicines contributes to continuity of care in that the medical care needs of the recipients remain uninterrupted (Woodward, Abelson, Tedford and Hutchinson, 2004).

On the contrary, the caregivers who cared for the care-recipients who were not identified as HIV and AIDS or TB patients including those who had tested positive for TB but had other opportunistic infections were constrained in accessing medical care. Although most caregivers received support in the form of food parcels and occasional assistance from the community caregivers – other forms of social response to HIV and AIDS illness – the major difference was that they paid for the health care services from the pocket. They could not anticipate the possibility of obtaining free treatment from the hospitals because their understanding of the care-recipients' diagnosis did not situate them within the 'free health care package'. The gravity of these experiences is obvious when considering that in AIDS care the myriad and distressing symptoms which the caregivers frequently experienced compelled them to seek medical care (Nilmanat and Street, 2004) and the erosion of household resources did not mean this need diminished. Although it was a common experience to involuntarily provide home-care without medication, especially during the advanced AIDS stage, for the non-TB/HIV/AIDS caregivers, inability to pay for healthcare hastened transition to caregiving devoid of medical care; that is even before the patients' physical incapacitation could constrain ability to reach the hospitals. Therefore, consultation fees, transport costs to hospital and debilitation posed a challenge for many family caregivers.

In the developing countries, it has been observed "a health care financing strategy that places considerable emphasis on out-of-pocket payments, whether to public or private health service providers, can have serious economic consequences for households" experiencing chronic illness (McIntyre, Thiede, Dahlgren and Whitehead, 2006: 863). In the current study this factor had far-reaching consequences for access to medical care, an extreme form of deprivation being caregiving without the essential medicines at home. When it was not financially feasible, the caregivers postponed hospital consultations despite their perception that the patients' condition required medical attention. Certainly, this situation was a major psychological stressor because the caregivers recognized deficiencies in their capabilities relative to the enormity of the need (Aneshensel, Pearlin and Schuler, 1993) to be responsive to the cared-for. The empirical assessment of the symptoms and their subjective experience thereof necessitated action. Medications were a necessary form of psychological support for caregivers, that is, even though they had limited clinical efficacy, as the disease advanced and more challenges emerged it was imperative to give the patients medicine. Ironically, the patients' biophysical condition could inhibit access to medical care as some symptoms were also socially constraining.

From this perspective, the protection of the PLWHA by confidentiality and 'glossing-over' the HIV and AIDS diagnosis seemed to exacerbate stress in caregiving because it deprived the care-recipients of the required medical care. In this way the strategy seemed to support the argument that HIV and AIDS care involved rationing and subtle demedicalisation because the caregivers could not pursue free treatment on the patients' behalf while diagnosis did not classify them as such. Without such licensing, they were constrained in their help-seeking behaviour because they had to consider both transport costs and consultation fees. This situation led to some caregivers suggesting that the care-recipients' access to medical care would be enhanced had they been diagnosed with TB. The positive view about TB among the participants had to do with the perception that it was not only freely treated but also had positive prognosis because the hospitals could effectively treat it. It seems surprising though that some caregivers would consider TB diagnosis positively given that co-infection with HIV and AIDS has been noticed since the 1990s. But this perception could be an outcome of the glossing-over strategy in a public health policy which emphasises chronic illness instead of HIV and AIDS where home-based care is implemented even though the AIDS epidemic was the main reason for this policy shift in care. It also highlighted the significance of diagnosis as known to the caregivers in the experiences of the caregivers.

Irrespective of the circumstances surrounding the experience of the symptoms, the doctors were expected to play their traditional role in illness experience – diagnosis and prescription. It was beyond the caregivers' comprehension that medical experts could fail to provide precise and accurate diagnosis. Similarly, the fact that doctors could prescribe medicines which they knew would not optimally suppress the illness was criticised by the caregivers who were aware of this situation. The perception that some doctors did not follow established treatment practices in terms of diagnosis and prescription constituted another stressor in caregiving. Some prescriptions were viewed as unconvincing. For instance, the caregivers were convinced that some of the treatments were 'useless' since they did not match the medical diagnoses. Van der Geest and Whyte (1989) refer to the "metonymic" relationship of doctors with medicine in that by prescribing medicine the doctors extend their healing hand to reach the patients and offer them assurance that the situation may be brought under control through the ritual of prescribing. The success of modern medicine has been linked to its ability to make interventions which directly put the disease under the spotlight through the clinical gaze instead of relying on the appearance of the symptoms and interpretation of the patients' narratives (Armstrong, 1995; Lachmund, 1998). It has also been argued that lay people mainly consulted health care facilities to obtain medicines and that they had "clear ideas of how the drugs should look and what effects they should have" (Sachs and Tomson, 1992: 314).

The absurdity of the norm of prescribing in this regard was experienced where the healthcare providers disclosed the AIDS status of the patients while at the same time indicated that the prescriptions were not optimal treatment. The caregivers perceived it anomalous for doctors who had the knowledge of what should work to consciously prescribe unsatisfactory medical treatment on account of cost. This practice defied assumptions about the benevolent character of doctors. Although misleading, it appeared that it was easier for the caregivers to accept that treatment was unavailable than to accept the cost-related explanation because the former gave the impression that the problem was universal while the latter bolstered feelings of deprivation. The epidemic exacerbated rationing in health care and empirical evidence in sub-Saharan Africa points to the predicament of family caregivers who cannot afford the medical fees and as a result forgo biomedical drugs which they are told would treat the illness (Bindura-Mutangadura, 2000).

Understandably, doubt crept in when the doctors failed to implement effective treatments. Mishaps such as relapse into illness or death evoked disappointment, hopelessness or anger. While this instability created confusion given the dominant status of the biomedicine tradition in society, especially in relation to specific diseases which hospitals were believed to have conquered, some individuals or institutions were criticised for their approach to health care which did not prioritise preservation of life. The view was expressed where the caregivers felt that the patients were deprived of medical care. They suggested that the doctors and by implication the hospitals, had replaced the care ethic with commercial interests. However, this may not be a straightforward matter in economies which are multilateral donor-driven and are operating under stringent budgets. Therefore, the hospitals' overall prescription policy to treat the opportunistic infections without medical attempts to reduce the HIV viral load which threatened the immune system constituted inadequate but 'affordable' medical care from the institutional perspective. Therefore, this approach would not be divorced from the "explicit rationing" policy with regard to AIDS care in the developing countries. Gross (1994: 20-21) describes explicit rationing as "policies that limit access of a population group to a particular medical service, facility, or technology. Access may be barred on the basis of financial, demographic or geographic characteristics" and the financial dimension may include regulating by user-fees. Lack of access to ARVs was an indication that the concern to curtail costs on a disease which produced symptoms which led to loss of dignity and extreme suffering drove the disease to the fringes of medical care. This aspect creates a link between rationing and demedicalisation.

Ordinarily, contemporary medical practitioners would not spend resources treating a persisting cough exclusively with an expectorant, or chest pains with an analgesic when tuberculosis had been diagnosed. From a critical view minimum medical intervention suggested that since from the medical perspective, the treatments were not expected to provide the possible optimal treatment, the prescription of drugs was mainly symbolic. Medical drugs have social meanings and are part of the social practice of biomedicine. As Sachs' analysis of medical encounters and prescribing in rural Sri Lanka illustrates, among others, doctors prescribed medicines as a ritual, an indication of concern on their part and a way of reducing ambiguity inherent in consultation concerning the nature of the complaint and the solution to it (Sachs, 1989). In this way medicines could be seen more as a 'token' meant to soothe the emotions, especially anxiety of those who sought medical attention while also maintaining normality in medical encounters than as therapeutic technologies; yet at the apparent expense of loss of confidence and status to the medical practitioners. In a situation where the symptoms rather than the underlying virus were curbed, it was inevitable to perceive the medicines as "impure placebos" that is "drugs with some pharmacological action that is not immediately or seriously relevant to the clinical problem" (Spiro 1986 cited in Whyte et al, 2002: 29-30). However, the family members would find it abnormal for medical encounters to end without prescriptions (Sachs and Tomson, 1992) because they are inherent to the healing relationship. In the context of home-based care, efficacy of treatments or lack of is realised away from the doctors but still reflects their actions.

Various medical interventions were perceived as inappropriate because they were inconsistent with the established treatment practices as known to the caregivers. This was mainly the case with TB because many caregivers were conversant with the regimen as provided in the hospitals as well as the outcomes. The drugs seemed to have lost their known effect and this was also observed in some cases with traditional medicines . The doctors' prescription practices too did not meet the caregivers' expectations and this led to pessimism and doubt about the intentions of the doctors. Some of these experiences could be interpreted as reflecting errors inherent in science as a human conduct. Stimson (1974) points that patients assess doctors' actions against a subjectively derived yardstick:

> Thus the medical rationality which may be seen by the doctor to back up his decisions will not necessarily be accepted at face value. After all, doctors *can* make mistakes and everyone knows doctors who have made mistakes. So people are able to... evaluate what the doctor does against what they themselves know about illness and medicines (Stimson, 1974: 102 – emphasis original).

Mistakes and uncertainty are not usually mentioned in medical encounters. But the practices described in the study suggest "faulty prescribing by professionals" for a variety of reasons including their attempt to meet the social expectations of the patients and caregivers (Whyte et al, 2002). Certainly, this explanation does not rule out the possibility of a critical view of these practices as illustrating nuances of non-compliance on the part of health professionals. In other words, the experiences illustrate that non-compliance cannot always be understood exclusively from the perspective which finds blame in the patient – in this case the health professionals' behaviour was equally crucial in bringing about desired effects of medication use. Sachs and Tomson (1992: 314) refer to Trostle's insightful characterization of compliance as an ideology which presupposes and rationalizes the authority of the doctors. Ross (1991: 89) also defines "professional non-compliance [as] the failure to follow recognized practice". It entails "inadequacies in the organization of care, and discrepancies of professional knowledge" (p. 89).

The caregivers had poignant and disappointing experiences with the outcomes of medical treatment in the long-run. The notion that the medicines did not work or exacerbated the symptoms was pervasive. Although some caregivers compared the different forms of treatment which brought about varying degrees of improvement in the quality of life of the care-recipients, hence moments of pleasure and encouragement in their role, in many situations such effects were limited. That is, while they helped to improve some of the symptoms, they failed on others or even led to new problems. Sometimes moments of improvement were transient. Their taken-for-granted assumptions about the curative power of medicine in general and of specific treatments for diseases which the hospitals were known to treat effectively were shattered when they realized that the regimens did not produce desirable outcomes. Suffering continued unabated and recurrence of illness occurred while the care-recipients' loyalty with treatments was not doubted. Clearly, these observations were in contradiction with the rationalist understanding of medicine in the twentieth century. This period witnessed unprecedented innovations in medicine which enabled medical professionals globally to improve the health of the populations and control disease (Whyte, van der Geest and Hardon, 2002) especially communicable infections. Although it is common knowledge, particularly in the western societies that medicine has limited curative powers in the context of chronic illness and some aspects of medicine are threatened by "identity crisis" (Bury, 1997), the same may not be said about the developing world. This could be attributed to the perceived belief among the lay people about the "infallibility of modern medicine and the magical power of prescribed drugs" (Sachs and Tomson, 1992: 313). In particular, anthropologists have commented on the significance of medicinal substances in the developing societies: "...they are believed to contain in themselves a power to transform the human condition...the substance itself is perceived as efficacious, allowing therapy to be separated from the skill and knowledge of the therapist" (Van der Geest and Whyte quoted in Hunte and Sultana 1992: 1385). This aspect is also illustrated by Nilmanat and Street (2004) who found that Thai caregivers of AIDS patients at "early stages of the disease progression" had faith in biomedicine and used it consistently because of their belief in its efficacy in cure.

In the HIV and AIDS era medicine yielded to disease substantially but unless lay people were informed about the implications of these changes for their specific caregiving contexts it was difficult to attribute poor response to medical treatments immediately to declined immune system due to HIV and AIDS. Doubt and cynicism were expressed about the health care professionals and not in relation to inevitable inefficacy of the medicines. Perhaps this was the result of limited information regarding diagnosis and prognosis of the illness due to adherence to confidentiality. The major contradiction, however, may be that the participants in the present study experienced drug inefficacy at the time when in the developed societies major strides in HIV drugs development continued to save lives thus producing positive experiences (Carricaburu and Pierret, 1995). Karasz et al (2003) have also suggested that the physicians' experiences with HIV highlighted the significant change brought by the drugs, by restoring the "myth of a good doctor" and improving the quality of life of HIV/AIDS patients who without this form of intervention could have died. Persson (2004: 46-47) also describes the inclusion of HAART as "a turning point in the epidemic in the Western societies" whereby the "discourse of HIV/AIDS as 'chronic' and 'manageable'… actually coincided with drastically 'shrinking obituary pages' (Rofes quoted in Persson, 2004: 47). Without adequate medication existential concerns competed with the need to maintain hope.

The fundamental experience was that the medicines ceased to have the magical effect. It was particularly perplexing to find that such poor response to medicines was experienced with young people who from the cultural perspective should respond readily to medical treatment, maintain productive life and economically support the dependent generations. For the caregivers who did not have medically supported information regarding the HIV and AIDS status of the care-recipients, such observations reinforced their suspicion that they were the victims of the doctor-patient secret. And there was a significant change in how the illness was interpreted. The perplexing characteristics of the symptoms – protracted, poor response to medicine and its selective impact on productive individuals – could have easily landed the illness in the "unnatural illness" categories traditionally believed to be caused by unappeased ancestors or witchcraft (Flint, 2001). However, their choices of treatment were predominantly biomedical oriented thus suggesting little evidence that traditional beliefs negatively impacted on the efforts to control HIV and AIDS. Instead, the traditional herbs were reported to have produced desirable outcomes.

There is glaring evidence that despite the inadequacies of the health care system and confusion, most caregivers did not resort to the traditional health system while there was also ambivalence about their effectiveness, as expressed by a caregiver who was a traditional healer himself. This is a perplexing empirical finding in a cultural setting where the use of traditional medicine is a dominant practice. However, other explanations could be the fact the caregivers did not associate the symptoms with supernatural causes and they trusted the efficacy of hospital medical treatment with the communicated diagnosis, especially TB. Poverty would also prohibit the use of diversified health care services including traditional doctors and private practitioners because the cost of their services would be unaffordable in the long-run. Moreover, the phenomenological method does not encourage probing which is guided by the researcher's preconceived ideas about how the social world work during interviewing.

While the perception that the medicines did not meet the expected standards was pervasive among the caregivers, it had different behavioural consequences for them. Unlike the patients, whose health beliefs and attitudes towards medication have been found to consistently predict their behaviour regarding utilisation, this analysis suggests otherwise about the caregivers. The tendency to evaluate doctors' actions including comparing them with personal expectations has been identified as relevant for understanding patterns of drug use from the patients' viewpoint (Stimson 1974; Conrad, 1985; Britten, Stevenson, Gafaranga, Barry and Bradley, 2004). It is clear that although such practices affected caregivers' experiences, they did not undermine the commitment to medicine use. They believed that medicines were essential and were devoted to ensuring that there were no treatment disruptions. In fact, even the caregivers who doubted the prescriptions persevered to help the care-recipients to follow such treatments consistently. For instance, the caregivers made effort to have medications available and ensured that the patients took them even in their absence. Their endeavours to ensure regular intake of medication included borrowing TB drugs, consulting the hospitals on behalf of bedridden patients, encouraging the patients to persevere and, assisting or accompanying the care-recipients to attend regular check-ups at the hospitals. To prolong medication use they persuaded, deceived or coerced the care-recipients who sometimes experienced symptoms which prohibited intake of medicines and expressed aversion to the medicines (Britten et al, 2004) or loss of hope about survival. Both the practices of the doctors and the behaviour of the care-recipients were vital in producing either positive or negative experiences for the caregivers.

These findings may be attributable to the intensity of the symptoms, the anxiety they induced and the cultural meaning of biomedicine in modern Lesotho. Crawford (1994) indicates that serious illness is experienced emotionally, but it is also true that pain and fear in caregiving relationships is experienced intersubjectively. Medicines contributed meaningfulness to illness situations because by administering treatment, the caregivers expressed their perception that the situation could be controlled, that the care-recipients deserved medical attention and care which included medicines while going without medication suggested lack of responsibility and inadequate care. Whyte et al (2002) indicate that medicines have both pharmacological efficacy and social efficacy and argue that "Medicines are socially efficacious because people share a common set of images and ideas about them" including the fact that they symbolise care while they may also threaten established order between the social actors involved in the providing, administering and taking of the medicines (Whyte et al, 2002: 31). Furthermore, the seeming lack of consistency between the caregivers' expectations and perceptions on the one hand, and their experiences with the outcomes of treatments illustrate what Williams and Calnan (1996) have suggested, that the simple dichotomies used to characterise lay people, for example, as believers or cynics may not hold in contemporary societies in which uncertainty is a dominant aspect of life. Demedicalisation of AIDS care was bound to produce unpleasant experiences in these caregiving situations because medical treatment was considered absolutely necessary in treating the illness.

The caregivers actively sought certain treatments on the basis of their experiential knowledge derived from informal caregiving. Their perception, however, was that the doctors disregarded their views on what could help the patients' condition and they interpreted this as the doctors' implicit intention to hasten the patients' death or lack of professional interest in the patients. As a result, where the condition of the patients deteriorated or death occurred following use of such 'futile' treatments the caregivers expressed indignation towards the hospitals and blamed the doctors for withholding medical care. The ambivalence of the authoritative status of doctors in their experiences was apparent. This form of the power-knowledge lobby is consistent with the ideals of the demedicalisation thesis because the lay populace sought to contribute their perspectives to the illness experience during medical encounters, as derived from their daily observations at home. However, the caregivers' experiences suggest that the doctors preferred maintaining their superior position during consultations to inclusive approaches to care. This attitude forecloses lay perspectives even though home-based care should ideally empower the caregivers and families about HIV/AIDS. It is also inconsistent with the view that lay people needed to be empowered with information but also because they gained knowledge which sometimes replaced medical views in the management of chronic illness.

Therefore, another aspect of caregiving experiences about medicines was about the discrepancy between how the caregivers expected the care-recipients to behave in relation to medication intake and their actual tendencies. They had negative experiences when the care-recipients voluntarily stopped taking medication and expressed disillusionment. These were some of the patterns of behaviour which social scientists have explicated using such terms as aversion, adherence or compliance depending on whose 'interest' they espouse. There is consensus, however, that aversion to medicine or non-adherence is a common behaviour (Conrad, 1985; Karasz et al, 2003; Britten, Stevenson, Gafaranga, Barry and Bradley, 2004) and that the analytic concepts for this behaviour tend to be value-laden. Given the role which the informal caregivers played as doctors' proxy their experience with the behaviour is worth considering.

The consequences of similar behaviour have been reported in HIV/AIDS care among the physicians frustrated by the late-stage HIV patients who would not cooperate with the professionals in drug adherence. Karasz, Dyche and Selwyn (2003: 1612) described the problem of non-adherence in the era of HAART as distressing and frustrating for the physicians. They stated that "...there was a special anguish associated with watching patients become sick and die because they would not accept the life-saving treatment" (Karasz, Dyche and Selwyn 2003: 1612) and these feelings were part of the reinstated role of a physician as a technical curer following the development of HAART in the developed societies. This is because the HAART cocktails reduced the threat of AIDS by suppressing the HIV while allowing the immune system to improve (Persson, 2004; Nattrass, 2004). In the present study behaviour which contravened the norm of 'medicated care', whether it was by the doctors who made 'anomalous' prescriptions or by the patients who subverted prescribed drugs, was distressing. Barnhoorn and Andriaanse (1992: 292) state that "[p]erceived social support from family and other sources on cooperation with medical treatment is considerable". But insistence on adherence could also be viewed as attempts by the caregivers to maintain a positive outlook amidst their frustration. In other words, it was part of the "emotion work" which caregivers have been reported to engage in, for their own sake and the sake of care-recipients, when illness is life-threatening (Thomas, Morris and Harman 2002). Furthermore, the different emotional experiences occurred when the same behaviour was exhibited during the different stages of the disease progression which basically suggested that there was a stage when the caregivers were permissive and allowed the care-recipients to exercise autonomy with regard to taking medication; and this usually intensified feelings of loss reported in long-term family care (Magliano, Fiorillo, De Rosa et al, 2005) and sometimes it marked the beginning of bereavement.

The care-recipients' "rational acceptance of death" (Karasz et al, 2003: 1613) was described as touching and devastating because the caregivers hardly gave up on the potential of medicine to improve the symptoms; they expected the doctors to make appropriate reviews and improve prescriptions. Some also hoped that with perseverance the care-recipients might see the day when suitable medicines would be available. Therefore, they looked forward to check-ups as times when medical refills could be made and feedback about their situation provided. Their emotional experiences including encouragement, anger and helplessness when the care-recipients did or did not take medication indicated the significance of these technologies in their *lifeworld* of caregiving. They also highlighted that the caregivers espoused the dominant medical view regarding drug use by patients which did not recognize the ability by patients to evaluate their situation and the prescribed medicine and on the basis of that decide on suitable action (Stimson, 1974). These findings confirm the view that social support by the family plays a significant role in the use of medical treatments by patients who are chronically ill and are not under hospital surveillance.

CHAPTER SEVEN

EXPERIENCES WITH PATIENTS' BODIES AND BODILY CARE

Chronic illness may affect human bodies profoundly causing pain and disability which necessitate care by others such as family members and health care professionals. Apart from medicines, the caregivers used food and bathing to ameliorate the symptoms and prevent physical deterioration, but the outcomes differed across situations. While giving the patients medicines was mainly done according to the doctors' instructions, providing food and helping the patients with bathing were techniques mainly used because the caregivers considered them part of their ethic of care. Feeding and bathing the patients were responses to illness and externally observable conditions which the caregivers intended to halt. Performing these activities in caregiving was also perceived important because they complemented medical treatment. All the care techniques were significant because the caregivers had profound beliefs that they could ameliorate the care-recipients' situation.

In this chapter the caregivers' experiences will be analysed to demonstrate that the bodies of the care-recipients were central to the consciousness of the caregivers, a rich source of stress and the medium of caregiving and care-receiving. Firstly, the caregivers observed the ill bodies and the changes in terms of physical appearance and ability. For example, those who witnessed the onset of illness observed that the patients' bodies were changing and getting thinner sometimes without the patients reporting illness, while those who encountered the patients when they were already ill perceived the patients' suffering through what they observed about their bodies. Overtime, they were challenged as the bodies lost the capacity to perform basic functions such as self-care, mobility and the ability to regulate internal processes such as bowel movement. The need to provide personal care also raised consciousness about bodily substances which they disliked and feared to touch because they perceived as dirt or as posing the risk of HIV infection. The chapter considers the emotions which were induced by the changes in the patients' corporeality, that is, the sympathy and the distress produced by observing and handling the suffering bodies during caregiving in a family context. What they observed and perceived of the bodies formed an important part of their experiences because their perceptions also influenced their orientation to care. It was significant, however, that despite the stress which ensued in providing bodily care, the caregivers persisted to provide care.

Secondly, the idea that the process of care entailed "care-receiving" was undermined in many situations by the care-recipients who seemed to disregard the caregivers' efforts and failed to take care of themselves, follow instructions and cooperate in caregiving while their bodies' non-responsiveness to care also produced stress. This analysis underscores the significance of food and how the concern with nourishing the bodies and the patients' behaviour in relation to food affected caregiving experiences. Food and feeding the patients were of high symbolic and instrumental value. The caregivers made effort to maintain food intake even under difficult circumstances and had positive experiences when the care-recipients consumed food or demonstrated physical changes linked to eating. Thirdly, the analysis indicates that maintaining aesthetics and demonstrating care through bathing was complicated by the social meanings inherent in touching the bodies of others and the desire by the cared-for to maintain autonomy and secrecy about some of the symptoms amidst constraining illness. Consequently, some caregivers perceived the care-recipients as unreceptive to the care rendered. Basically, caregiving was predominantly stressful in this realm because the caregivers expected the cared-for to respond to care, to be grateful and behave in ways which augmented caregiving efforts, yet, there were circumstances which threatened care.

Observing the body and perceiving the suffering

It is common to survey the bodies of the people who we care about and the changes we detect usually alert us to their inner state and condition of health. The caregivers had the tendency to monitor and compare the patients' conditions across time and could discern worsening conditions from improvements in their respective caregiving situations. The care-recipients communicated and expressed the pain which affected the different parts of the bodies. But the caregivers also sensed their suffering when they observed their corporeality. Caregiving was complicated by the emotions which emerged from discerning the changes which tended to affect most of the body systems, usually from better to worse states. They observed the changes in physical appearance and the declined capacity of the care-recipients to perform social roles including their inability to meet their personal care needs. Although the duration of the process of this deterioration and the extent of such consequences differed, some of the participants indicated how these changes affected their perception about the health state of the care-recipients. A caregiver who experienced abrupt decline which suddenly led to death said:

> *He only became very dependent in the last two weeks, that's when he could not bathe himself at all. That hurt me a lot, just seeing him in that condition; it was unlike him. He used to be a very strong person who would do anything and he did not choose jobs even the most difficult he just did them. It touched me to see him in that condition. He had lost a lot of weight because he did not eat well; he refused even the tablets that would sharpen his appetite (Spouse2)*

Such bodily changes tended to be experienced emotionally as they eroded hopefulness in caregiving. Other caregivers stated:

> *… I am talking about someone who used to wear a size 44. What you see now is not her even though she is much better, but she cannot wear any of her clothes now because she is still below her normal weight… I think the whole situation was not good because I could not bear the pain that she was having (Mother3)*

> *She cannot leave her bed any more so she needs to be cleaned all the time so that she stays fresh. We use the powders that my aunt provided to keep her fresh and they help a lot…this time I don't have hope because she is not responding to anything, even when I touch her hand, it is as if she does not feel anything. I tried to put water in her mouth because I thought that her mouth could be dry, but she does not swallow, the water just comes out…she does not eat too. I wish I could cry too, but I don't have tears at all (Daughter)*

Perceiving pain and touching the bodies

The perceptions that the care-recipients were suffering led to the caregivers empathising with them. Their thoughts that pain was diffused in the bodies and their imagination that it was constant were distressing. They also worried that they exacerbated the patients' discomfort when they handled their bodies; this was sometimes confirmed when the patients complained that touching their bodies hurt. They responded with grief and compassion but it was also a dilemma because touching the bodies was integral to caregiving and was intended to relieve pain. One caregiver said:

> *This person is in serious pain. She spends most of the time in pain and I feel pain inside me because I stay here with her day-in-day-out. When I am with her a lot of times she is in such pain and when she is in pain I always wish I could know what would help her feel better and what I could give to her because when she is like that her tablets do not help much. I try to give her the painkiller that she gets from the hospital but it does not help because sometimes she cannot even take her medication. I am suffering too. When she is very ill I just sit here with her watch her in pain. And*

> *at this time she does not even talk to me, we just sit here and sometimes I wish I could have someone who could talk to me so that I become preoccupied with something other her suffering (Sibling)*

Another described his dilemma:

> *I sometimes feel scared when he cannot bathe because I help him but I am afraid of a very sick person. When he is too ill I become very scared of helping him, I am afraid to touch him because he is in such pain. When he's very sick, I shake with fear because I have to bathe him because he is so weak (Son).*

One caregiver expressed this tension as follows:

> *I fear because I get worried that I could be hurting him especially when he has wounds [sores]. Besides, I am very scared of a very sick person; it bothers me very much to see someone very ill. When he is so sick that it is like he threatens to die at any time I become scared even to touch him. I can't lie; I am scared of that situation (Uncle1).*

Other caregivers explained why seeing and handling the bodies of the patients tormented them. Since they provided care to people whom they cared about their daily interaction with them and the close contact with their bodies profoundly affected them emotionally. They experienced emotions such as fear, pity and sympathy.

> *There were things which scared me. I got frightened when I tried to hold her and turn her; I did not know how to handle her because she was 'finished'. I felt like I was hurting her. I was always shocked when I bathed her because she was my child and I had never seen her like that. I just felt shocked and bathing her was the most distressing time for me, but I made sure that I bathed her all the time because I did not wish her to die in a bad state… When this old woman was not there I just turned her from side to side until I finished. I could not stop sympathizing with her and it was my first time to nurse someone for such a long time (Mother1).*

> *I suppose when you are a mother and your child is in such pain you have no choice but place yourself in her shoes and that sucked out my energy, I became exhausted because I could see that she was really suffering. I was hopeless but there were times when I could see that she was trying hard to be strong. When she did that I pitied her because I could see that it was difficult on her part but she was trying to give me courage (Mother3).*

> *He was finished, it had finished him. He was bedridden and he was completely finished all that was left was bones. I continued to care for him and I was kind to him, I did various things to help him feel comfortable. I would go to one girl here who works at the hospital and she would tell me about different things that are useful, especially to help his body to be comfortable and good looking (Grandmother)*

Another caregiver described how different forms of discomfort affected his emotions and caregiving.

> *But at present as you have seen it [skin rash] is really all over his body. It started in November last year and since then it does not disappear or heal it is always there though it may become milder for days. It even turns into blisters which after sometime become sores. As it is now I would say he is much better. We see him as much better… because there are times when he becomes really worse. You can pity him. When it is in this condition I think it feels itchy which I find better but when it becomes blisters it becomes both itchy and painful. You realize that when he is being bathed, you can see him twitching his face that he is in pain. When it becomes sores, well, it becomes really difficult to handle him because he feels pain. You can see that he is pain… (Uncle1)*

Their perceptions about the symptoms and the physical changes, and their emotional experiences, especially fear could threaten caregiving because they contemplated avoiding interaction with the patients. The feeling that the symptoms were overwhelming created the desire to break away from the responsibility temporarily and resume later when they had subsided. While obtaining respite from other family members or hospitals was a useful coping mechanism for those a few who had it, the caregivers occasionally felt incompetent in this role for various reasons. Some stated:

> *I wished I could have someone doing it for me but what could I do because it was obvious that no hospital wanted her. She was very unlucky I guess… (Mother3)*
>
> *I don't know but I had began to be afraid because her whole body was in pain, everywhere I touched her because she had sores everywhere (Aunt)*
>
> *I get discouraged when he is very sick. It is my serious weakness because…I become so afraid that I cannot even bathe him. My wife knows how to handle him…during such times I find her to cope better with the situation... We help each other…But there were times when I would not even want to be anywhere near him; I would stay away confused just waiting for anything to happen. That is why I am hopeful that may be he will grow up because experts may come up with a solution for this disease (Uncle1)*
>
> *I don't know it is just that I am even afraid to sit with her… I don't like the sounds that she has started making… I didn't want when she [younger sibling] heard these sounds but I didn't know what to do. The main problem is at night because it becomes so quiet and when she is making those sounds, it is painful… we couldn't sleep at all. She is in pain. Yesterday night I crushed a Panado and mixed it with water and helped her to swallow it, but she couldn't so we put it under her tongue so that it would melt. I was very terrified but thanks to the presence of my aunt. I guess I cannot face it. It is my first time to see someone this ill (Daughter)*

Difficult moments introduced feelings of self-doubt among the caregivers who felt that they were incompetent to deal with the situations either because they did not have past experience in caregiving or the current situation was extreme. They developed anxiety when the patients' health conditions continued to deteriorate thus increasing the chances of providing intimate bodily care. Touching the bodies of the patients evoked fear and painful feelings because through touch, they experienced the effects of the illness on the patients' bodies differently – it brought the caregivers closer to the suffering and aggravated the feelings of sadness, and it could lead to a desire to escape while also increasing their sense of obligation towards the patients.

Perceiving physical appearance and feeling the body

The caregivers also perceived the bodily changes negatively. They compared the physical appearance of the care-recipients prior to illness or what they perceived as healthy looks or signs of life. Some of these changes were extreme loss of weight and changes in facial features. Most importantly, these changes revealed aspects of the body such as bones and veins which ordinarily hid within, thus bringing death thoughts to their consciousness. One caregiver indicated that seeing the patient was discouraging as she believed the patient was going to die soon. The patient's condition did not make her feel hopeful about the future. She said:

> *You could see her blood veins through her skin. I could see her bone structure through her skin and how could you expect such a person to live. Her veins were exposed and the hair was very weak. I was convinced that she was dying. She was very pale – her complexion, she was as if she does not have blood, her eyes were very white. I was not counting her among those who will still be breathing today (Aunt)*

Two mothers expressed the emotional pain they experienced as a result of seeing such deterioration with their children's bodies and touching them:

> *But as you can see she is much better because at that time she had lost so much weight. I'm telling you all that was left was the skin and bones only… It was hard. But for me mostly because I had to wash that body every day… But at that time things were worse. She was bony. I had never seen anything like that: I did not know that the pelvis bones and the sockets that combine the lower abdomen to the limbs, that there are cavities there which can remain without flesh, I could not believe it when I saw that even when you touch or feel her there was no flesh at all, and every time when I touched her I felt this pain deep down in me. I was wondering what kind of disease would do this to a human being. And she would also touch herself and feel saying that all her flesh was gone… her skin way grey and very dry, when she scratched it peeled. We applied Vaseline but it did not help, her lips were chapped and she was miserable, her eyes were very white. If you saw her you would also pity her. (Mother3)*

> *…yes, they are not relatives of ours but they treat us like family. Even now they just visit and I chat with them. I am the one who asked them to stop bathing her. I think I am the one who should handle her now. She is too ill, and she has lost so much weight, what you see there are blankets. My child is eaten away by this illness, but I cannot lose hope, not now. I just don't want to cause them*

> *the pain which I feel every time when I touch her. All the time I think, this person has lost so much flesh, it is not nice to see her like this, it is not nice and when I touch her I feel a terrible pain in me. I don't know what is happening but I will not stop praying God (Mother4).*

The changes in the patients' corporeality constituted a significant aspect of the caregivers' experiences. Touching and seeing the suffering bodies was experienced with pain and fear. For example, they described in detail the changes in body structure which shocked them and made it difficult to handle the body even though it was unavoidable in caregiving unless there was a willing and acceptable individual who could help. Since they dreaded extreme weight loss, feeding the patients and ensuring food consumption were priorities in caregiving. The caregivers expected the patients to be receptive to this form of care in order to realise comparable improvements with the bodies.

Perceived significance of food and eating in caregiving

Caregiving included thwarting the conditions which were considered to accelerate the progression of disease and reinforce the effects of the illness on the body. Apart from the bodily changes which marked the onset of illness the physical appearance of the patients continued to form part of the caregiving experiences. Of particular concern were the changes which were externally observed as announcing the non-responsiveness of the body to care. The most significant conditions were loss of weight and vitality which the caregivers feared because these conditions led to laying in bed for long periods. They tried to counteract this situation by providing food and ensuring that the care-recipients ate accordingly. Besides, food was integral to caregiving as it had several meanings in caregiving, including its association with maintaining life and the will to live.

First, providing food to the ill individuals was the essence of care and its significance was highlighted in different ways including the fact that the beginning of a new day was essentially marked by serving the patients food.

> *I would wake up early in the morning and prepare her soft porridge and give her medication. When I give school kids bath water, she has already had her morning dose. I then feed them and give this little pre-scholar her lunch pack. I send them off. After they have left I bathe my patient. I then cook food so that we could have lunch (Mother-in-law).*

Second, the frequency of serving food daily and the strategies which the caregivers used to ensure the patients' access to food also indicated that food was central to the care activity.

Some of the caregivers who incorporated caregiving into their multiple tasks established ways of ensuring that the patients had food even when they were not with them.

> *When I left I would place food and tablets next to her and go. At times she would eat; sometimes she would not (Aunt)*
>
> *If I go I always make sure that I leave food where he can ask even a visitor who walks in, if he can't get up he will ask a visitor like you, 'please bring me my porridge from the kitchen', or he calls the little girl to assist him. But every time when I leave I make sure that I make provision for food... (Son)*

Third, the caregivers' experiences when the desired eating patterns could not be maintained showed that inability to ensure the intake of food in caregiving could also be a stress-inducing condition. This was because the caregivers could not envisage recovery when the patients did not eat well since food was expected to change the physical conditions of the patients, especially loss of weight and vitality. A caregiver, who was concerned because she could not arrange a suitable place for care, indicated that the irregular eating habits of the patient contradicted her own values. She expressed her concerns thus:

> *There is a difference because when he is there I take large servings of food in the morning and he has to serve himself during the day. But when he was here I could do everything for him. It happens sometimes that I take food there but he is less motivated to eat and he just leaves the food there for the whole day...Then it means that he does not eat well. So when he is here it is much better because I can monitor him closely and ensure that he gets the three meals a day. Sometimes he falls asleep after meals and medication; he sleeps for too long and misses midday meals and dose. That means he would have had the medication once...It makes me feel bad because I know that he is supposed to eat three times a day, and if he eats once or twice it means that he is not eating enough. And it is wrong for someone this ill. When he was staying here he even gained weight, he was very much okay, but since he returned to his home he has deteriorated (Sister-in-law)*

Others mentioned:

> *That's the problem he caused us when he arrived here (at home). He would not eat anything...he would pick a little and stop. That distressed me because I was telling him that he should eat to regain his strength. He was weak because he did not eat well, that is when we put disease aside... (Uncle2)*
>
> *She would immediately vomit and would remain nauseous and not eat her food. I don't know if she could not swallow it because she was vomiting or if food caused her nausea. That was very distressing because she could not eat and I wanted her to gain weight and be stronger again. (Sibling)*
>
> *Eating is a major problem in this house. Sometimes I get frustrated when she does not eat because I think that she needs to eat so that she has energy (Daughter)*

The caregivers also believed that eating food enhanced the efficacy of medication.

> *I liked it when she ate because you see there is a problem if someone does not eat, medicines don't work, and you are immediately sure that this person is not going to live and how would I survive these three months if I did not have hope?...I liked it because she did not have a major problem with food. She only had a problem late when she started vomiting (Sister-in-law3)*

> *It is painful because sometimes a patient develops these crazy taste buds which do not like the simple food that we eat daily – pap and vegetables. And when your patient does not eat you get discouraged because there is no way the medicine will work. That was one of the major problems with my grandson, he would spent days eating just a little because he wanted to eat meat. Where do I get meat from in this age? (Grandmother)*

> *...again I did not like when she did not show hope about her life. It made me very weak. There were times when I would actually get angry and tell her that she should be encouraged (positive) so that the medicines can work (Mother3)*

Fourthly, not eating was a harbinger of death. The strong perception about the link between food and life influenced the caregivers' emotional experiences when the patients would not eat. The anti-food behaviour was perceived negatively because it intensified thoughts about death. The frustration emerged when the patients' attitude towards food did not seem to reinforce the efforts against the perceived 'enemy' – death or yielded to it. Some caregivers described how the onset of this behaviour distressed them and said:

> *He has surprised me because his appetite has changed. We try to prepare food that should swallow easily because I thought that he didn't eat because of the sore throat but even soft food...I try to talk to him because you see there is no way we can expect these medicines to work if the body is not receiving food. I think it is hard because his mouth has this white lining but I clean it... I don't know but he makes me think hard when he does not eat (Spouse3)*

> *There was a time when she did not eat properly... She had this relentless cough which led to her vomiting almost every time before she could eat. Whenever I mentioned that I would be bringing her food, she would start showing signs of nausea. She did not like anything going into her mouth and I was worried. (Mother3)*

Caregivers who had experienced death cited this behaviour as one of the signals that marked the onset of their bereavement. They recollected:

> *She was completely dry because at this point in time she had stopped eating for many days. She could not swallow anything...You could sympathize because she could not bathe, eat or do anything. (Mother1)*

> *...she did not vomit at all but for three days she started refusing food. On the fourth day, I gave her soft porridge in the morning...I wanted her to take her medication.. She ate and she said to me '24 hours'. I asked her what does 24 hours do. I asked: did you spend 24 hours in pain? But she did not reply me. Later on she repeated: 24 hours. And I said: "what is this 24 hours of yours? Or are you going to die after 24*

> *hours?" She just looked at me and she was already breathing with difficulty... That night, on the fifth night I realized that she was very weak and numb... When I woke up later at night because I used to wake up at intervals, I saw her arm lying droopily on the floor... When she saw me, she stared at me but with very weak eyes. I said to her: what are you doing woman? She closed her eyes... (Mother-in-law)*

Another caregiver experienced this behaviour early in her caregiving role and was disappointed with the patient who gave up subsequent to testing HIV positive. He was not very ill when they consulted the hospital and she constantly reassured him that she would fight the disease with him. She described his yielding with sadness:

> *He was so worried about 'it' that he even stopped eating. He stopped enjoying food and refused eating altogether. He was even saying that if he knew how effective poison could be, he would take it. He was so confused and I still believe that he died only because he agonized on this infection, if not he would not have died. If he could have accepted he would still be alive like me...he could have regained his body mass because he was getting medication. It was not his usual weight but not that bad because he was still eating well then. But things changed after we had returned from the hospital. He had been eating very well but immediately after he was told about the diagnosis his condition just declined (Spouse2).*

One of the participants who had experienced serial caregiving indicated that one of the patients suddenly refused food and medication because she was protesting that the medication did not make her feel better. This situation depressed the carer. She stated:

> *I did not know what to do. I would prepare soft porridge for her in the morning and persuade her to take it so that she would not take medicine on an empty stomach but she refused to eat and she refused to take medication. I told her that she needed to eat, but she refused. I was discouraged because I knew that if she was giving up it was going to be impossible to force her to eat. Adults are not children; you cannot force them to eat. But it made me sad...The same week that she refused to take medication and food, she died (Sister-in-law2)*

Another one said:

> *When his mother arrived she was not able to have a conversation with him because he had already spend days not talking, not eating...I saw him becoming miserable and he started talking about his mother more. He even said that if she does not come soon, she would find him gone. He said if she is taking long, she won't find him. Since he started saying this, I knew he was going. I saw him holding his breathe and just calm, I knew he was going. I'm sure he waited just that week to see his mother because he spent one whole week not talking, not eating and his bed was dry. He remained like that until his mother arrived and saw him and when she arrived he could not even talk and he died the same night (Grandmother)*

Another participant described the pain that he suffered when the patient resorted to the behaviour:

> *I wished I could hold her life but she was in pain and I remember one day I felt very disturbed because she stopped eating. I said to her please try to eat because you will be very weak and she said I am already finished. Those words, made my heart bleed I knew that it was over because all these*

> *time she had been ill, she would not joke about death, so I knew that she was leaving me. The pain that I felt was worse than when I realized that she was dead because when she finally died she was in so much pain I felt that if I showed sadness, she would hold on and her suffering would be prolonged. In the last week I had started praying for her soul because at this point I wished God could rest her. I even saw her sadness when she heard that her son had died. She said why does God not take me instead of my child? (Spouse2)*

Strategies for ensuring food intake

Since ensuring that the patients ingested food was vital, the caregivers used various strategies which included encouraging, persuading, coercing and feeding the patients. One of the caregivers indicated that he was vigilant and had requested the other family members to ensure that the patient ate as required. He said:

> *I consider her lucky to have a father like me because other men would not be this patient, some men would have given up long time ago. I have also taught these other children to watch her closely especially with food and if she eats less, they encourage her to have some more or at least supplement with soft porridge. They tell her, have more she also takes heed… (Father1)*
>
> *…I then fed her and she became stronger. I then realised that she was not eating well before. No one was persuading her to eat because they believed that she was spoiled. When she arrived here I took her slowly; at first she finished one spoon of papa, and slowly I increased her servings to two but she would eat just one and half (Aunt)*

The caregivers developed feelings of incompetence and guilt, but mostly frustration which could be discerned from their anger and use of subtle or explicit coercion when the patients did not comply and eat as they thought it was necessary, that is, finishing the servings and eating several times. Some caregivers stated:

> *In the last few days, she had a very poor appetite. I encouraged her to eat ...we should press her to eat because if she does not eat she will become weak. They would report to me that she ate a small portion, and I would sit down and encourage her to eat more and she tried until she finished her serving. I always want to be satisfied that she has eaten adequately, I watch her carefully (Father1)*
>
> *And she was a nuisance because when anyone came here she would be gossiping saying that I don't give her food and I abuse her verbally. It was true that I was speaking strongly to her about eating because I did not want her to skip meals and medicines. If she was all over the village when would she take her medication and how was I to see that she was taking them. I told her she is a heathen. She was a nuisance (Aunt)*

Some caregivers were strict and compelled the care-recipients to take food because they were anxious that unless they ate and regained strength, they would die. One participant indicated that the patient was severely emaciated when she first arrived home because she was previously deprived of care. Consequently her primary goal was to help the patient to recuperate and food was a critical part of the instruments used to forestall death. She said:

> *… I told her strongly that we don't have a pig here she should eat and finish her food. She began to eat better. Whenever she left food on the plate I would remind her that I work hard to get that food, so she should not waste it. I told her I do piece jobs to get her food. I reminded her that if she does not eat, the food is thrown away and that is wasteful. I realised that she was weakened by starvation because I think they would just serve her and if she did not eat it did not bother them. So she was being killed by hunger more than anything because you see if you are ill and you don't ea... I did not want her to lose energy so when she did not eat well I got worried (Aunt)*

Another caregiver who was frustrated by the poor eating habits employed more severe measures to compel the patient to eat. His view was that the patient was abusive to him and other family members. He recognised that the patient's behaviour was negatively affecting her baby who was breastfeeding at the time. He said:

> *I had a difficult time with my daughter… I fed her. There were times when she refused to eat saying that food does not taste good. I did not want to buy that so I would sit next to her with a stick and tell her to eat. I would thrash her lightly because I wanted to scare her so that she could eat. It doesn't mean that I flogged her but I would not let her do as she wished. Aa-ach…* (Expressing despair) *She delivered without any problems but after just two months problems started, the baby died. The baby was killed by hunger because the mother was not lactating well. This was because when she started being ill, she refused to eat, I'd try to persuade her and feed her but she would tell me she doesn't want food. She was already very sick but also very stubborn... (Father2)*

Sometimes it was appreciated that illness spoiled appetite. Some caregivers said:

> *She has this thing that makes her breathe with difficulty when she is in pain. When she is like that she cannot swallow anything, medicine or food and it hurts because you know that this person is in pain. Well, I have realized that these happen when she is too ill… (Sibling)*

> *Sometimes I think that she does not eat not because she is full but because she does not like the food that we give her. She does not even like the porridge that we make with the flour that we get from the (…) because she says it has a unpleasant smell. You know what illness does to appetite; even a mere cold will make you feel not like swallowing any food, what more if you are this ill (Daughter).*

But, it was difficult to tolerate the patients' reluctance or inability to eat. Feeding them when they were unable or unwilling to eat also significantly marked how the caregivers performed specific tasks on behalf of the patients. On three occasions, the researcher observed the caregivers feeding patients who could not open their mouths or swallow the food. For example, when a caregiver recognised that the patient's eating habits had nothing to do with her being full, but the taste of food, she persuaded her. She stated that:

> *We struggle when it is mealtime because it does not mean that I will just leave her like that when all the people in the house are eating (Daughter)*

One of the caregivers expressed her dilemma as she continued to feed a patient who was terminally ill – she could not move her limbs and her face was kept covered with a net to prevent flies as she could not close her eyes and mouth.

> *Now she cannot eat, she cannot swallow anything. She is fed this soft porridge, though it is very difficult because sometimes she says she does not feel hungry (Mother1)*

Failure to safeguard this component of caregiving produced stress because irrespective of the nature of the factors which led to inability to consume food, the behaviour was inevitably perceived as a threat to realizing improvement in their health. The value of food included its perceived co-effect with medicine.

> *I try to tell him that if he does not eat and does not take his medication, he won't become better and he will spend a long time sleeping or lying in bed. You will see that after some time he is convinced and he takes my advice…I tell him that he should eat because food will give him energy… (Sister-in-law1)*

> *That is why I make sure that she eats well even now when she is too ill so that she continues to have strength. Even at the hospital they help because they give her some tablets (multivitamin) which they say make her feel stronger and they say they weaken the virus* **(kokoanyana)** *in her blood (Sibling)*

Therefore, it was crucial that the care-recipients' attitudes and behaviour complemented the caregivers' actions towards ameliorating the physical changes which concerned the caregivers. In this way they contributed positively to care because the caregivers felt that they responded to their efforts. When the care-recipients consumed food, the caregivers felt encouraged and the fear that the health condition of the care-recipients would deteriorate subsided. They also compared the times when the patients ate and when they did not. Some said:

> *…when he listens it makes me feel encouraged that he will be better even if he may not be as healthy as he used to be. I tell him that food gives energy. I persuade him…when you are giving care to someone and you see improvement even if it is not complete healing, if he becomes better from that condition which was making him critical, I get some courage. I get the feeling that my advice and encouragement to him when I say 'take your medication, eat your food,' all that bringing the difference and making him better, it makes me feel good. (Sister-in-law1)*

> *One thing that made me happy was when I saw her eating well and taking her medication accordingly; in that way she gave me courage too because she showed me that she was responsible. I*

> *did not want her to lose energy so when she did not eat well I got worried. If she did not eat I got mad... (Aunt)*

Another one said:

> *But later she was ok again and she could eat well, now she reminds me about food and I am happy because she eats any food that we have, not like then when she was selective and did not like certain food, she eats about four or five times a day. And it is good because this virus should not get a chance to destroy her body. At that time she would eat just a little when she tried very hard, but now, she pushes anything down her throat (***oa lahlela***). She even reminds me...She asks for more. But I feel good when she eats well, it makes me feel hopeful (Sibling).*

One of the common experiences when the patients ate satisfactorily was encouragement and a feeling of hope that medication would be effective and that they would recover. The caregivers expressed positive attitude about behaviour which conformed to their expectations, saying:

> *He is now able to eat and he eats a lot and this gives me courage that he will be better... when he does that he gives me courage... But the body is weak but I still believe that a person will not recover instantly. Disease takes time to enter the body and when it goes it takes time again (Father3)*

> *He can even talk and he can eat, but anyway with food he has always had a good appetite even when he was very ill. That is what is encouraging about him. He eats well; it is just that he does not like the porridge that we make for him with this flour from (Agency) I don't know if I don't make it properly... He also complains that the beans cause him pains in the stomach. But he eats other food (Son)*

A caregiver who was disappointed by a patient who died despite eating well said:

> *Even her eating was encouraging. It is true that during the 15-day treatment the nurses said she was not eating well but once she was released her appetite improved. She enjoyed food and that encouraged me... She spent the two months after she was diagnosed doing very well, she was alive. She was eating well and although she was not completely cured I encouraged her to do her best and be strong. I felt encouraged and at lunch I would encourage her to wake up and prepare food for herself. She was doing well (Mother-in-law)*

In all situations of caregiving the caregivers were concerned about weight loss and they attempted to help the patients to regain weight and vitality through nourishment. They adopted ways of making the patients eat, including persuasion and coercion. Food was also perceived as a necessary element in caregiving because it facilitated the effectiveness of medicines. The caregivers experienced encouragement when the patients cooperated with them in this area of care because they could easily link their efforts with objectively observable outcomes such as increased vitality and weight gain. Unfortunately, such outcomes also gave false hope which could lead to devastation when the cared-for deteriorated despite such efforts. Any conditions, including the symptoms and the behaviour of the patients which impeded food consumption, produced painful experiences in the form of stress, anxiety, anger and pessimism. This included the tendency by patients to refuse food. The behaviour was mostly experienced at the advanced stage of illness or when the patients were in severe pain, thus bolstering the sense of hopelessness. Although the caregivers could sometimes justify the patients' undesirable behaviour they still found it equally distressing because it contradicted their caregiving goals. They defied such situations by continuing to supply the body with food because they perceived it as a thread that connected the body to life. Forcing the patients to eat was an expression of frustration because refusing to eat was interpreted as early signals of the patients giving up on life, being uncooperative or an irrevocable decline in their health condition which would also usher in the influx of other overwhelming conditions and symptoms. Deterioration in health condition introduced increased dependence on the caregivers for bodily care and new challenges.

Autonomy and resistance in bodily care

Protracted illness and loss of vitality introduced varying degrees of dependence among the patients and drew attention to other complexities involved in the care of others' bodies by touching and seeing them, yet both were inevitable in caregiving for the chronically ill. The caregivers' workload expanded because the patients could not cope with several tasks including bathing. Helping the patients to bathe was done for aesthetic, hygienic and health reasons and involved varying degrees of intrusion with the bodies of the cared-for. Generally, the caregivers encouraged the patients to help themselves for as long as possible, but intervened when they perceived it necessary. However, some caregivers encountered resistance when they had to access the patients' bodies for care.

Assisting to maintain autonomy and managing workload

The caregivers evaluated the situation constantly and provided minimal assistance when the patients were not severely ill. In situations where they became involved while the patients were already ill, they could recall moments of relative independence. Some said:

> *At the beginning it was better because she would say that I just place an old blanket and washbasin next to her, and she could bathe herself comfortably then. You would pity her no matter what... (Mother1)*

> *Because she was too ill, I had to bathe her every morning but since she could still wash that part, I did not bother... She would frown when touching there but I never thought that it was anything that serious (Mother3)*

> *He is one person who is very strong even when he is ill he really tries to lessen my burden because when I give him water to bathe he would volunteer to bathe himself... (Sister-in-law1)*

They recognized that bathing the patients was physically demanding, and although they empathised with the patients they did not bathe them when it was not necessary. Bathing the patients could also be complicated by incontinence and diarrhoea which usually set on when the disease was advanced. They were concerned about maintaining the patients and their place of care free of odour and preventing bedsores which could attract criticism and stigma. For example, some said:

> *I bathe him so that when people come here they don't find him unclean (Son).*

> *She is quite fine compared to other patients who are untidy and sometimes you cannot even stay in the same room with them for long because of odour... I felt that I had to forget about my fears. Fear to do this and that, I said it is no use to fear a sick person (Sibling)*

> *Of late the major work that I do is bathing her and keeping her clean in all ways; her clothes, her bedclothes and keeping her dry all the time...and I apply cream on her skin so that she feels good about herself. She used to be very smart and she took good care of herself... Because I think at that time she became too weak; she could not get on her knees and legs but she actually told me when she felt the urge to go to toilet but my fear was that it happened so fast and if I insisted on her using the toilet it would be messy... During the day I just wipe her lightly because we do major bathing in the morning ... (Daughter)*

> *...but when it comes to bathing and feeding the patient, I do it; it is me everyday...since she became very sick and bedridden, I bathe her or at least change her clothes but it is not easy because they are not just wet so I have to wash them and I can't let these children do it even though it is their mother... Her clothes need to be washed all the time because you know that when a person is too ill they cannot have the control that we have and she has to be fresh so that people will not think that we don't take care of her. Like now, I have been listening and her tummy making those sounds. I will have to help her because I don't like the sores you know, they make caregiving difficult and they make an unsightly patient and I don't like that (Mother1)*

The transition into increased dependence was challenging to the caregivers and it was one of the yardsticks which they used to compare their situations with those which they experienced previously. The fact that some caregiving careers did not involve this form of care, or it was provided for a short while only, could contribute positive experiences. A caregiver who generally perceived caregiving as a difficult obligation identified some of the aspects of the role which lessened her burden as the capacity of the patient to use a chamber-pot. Unfortunately, when the patients died in that state of relative independence, the caregivers were shocked:

> *… She was always able to squat on the chamber pot. She was never dependent to the extent that I had to turn her sides on bed or feed her. I was helping her with bathing. She never wetted her bed. That's why I'm telling you that she slipped through my fingers; she was not supposed to have died (Mother-in-law)*
>
> *He only became very dependent in these last two weeks, that's when he could not bathe himself at all. (Spouse2)*

Apart from increased workload, the change from being physically independent to a state which necessitated radical care could also be experienced with sadness because the change was associated with real decline in the health conditions of the patients. A widower who had been a serial caregiver was overwhelmed when he had to bathe his daughter and help her with a baby who was born during the onset of her illness.

> *I had a difficult time caring for her and the baby…I did everything for her, fed her and bathed her and the baby and you know that it is not easy when you are a man, but I didn't want her to complain… she could not even bathe herself and I had to turn her all the time and wipe her because she could not even go to toilet anymore (Father2).*

Another caregiver who experienced this change as marking a new trajectory in the progression of the illness and was depressed said:

> *I was very much discouraged. My husband collected him from there because he was really ill. At that time I had lost hope completely…he could not do anything for himself. We would bathe him, me and my husband because we had to help each other; it is not easy with an adult. We helped him even with minor things such as polishing shoes and combing his hair; he was very ill and weak (Sister-in-law1).*

When the patients' health state declined further to the extent that it was difficult for them to maintain personal care, it was imperative for the caregivers to take over. Therefore, they were vigilant when the patients experienced incontinence and spent a substantial part of the caregiving time on changing bedclothes, laundry and sponging their bodies to maintain the care environment clean. These were some of the areas of caregiving which produced stress because they were sensitive, emotionally draining and increased workload.

Disappointment with secretive care-recipients

However, the quality of care could be undermined if the patients did not inform the caregivers about some of the symptoms because they were embarrassed or intended to conceal them. A father said:

> *I would bring the washing basin and she just says no and she would go on for a week with that behaviour and I said to her, you are just wasting your time because you will finally come down…I just ignored her and I told her, calm down because I am going to bathe you, I will do it myself because you are stubborn. She would frown when I walk in and I began to realize that she does that when she has soiled her blankets. She had diarrhoea but she would not tell anyone when she feels the urge. These were some of the things we fought over. But even when she did not have diarrhoea she would just do it in bed and I realized that it was because she could not get up anymore or walk. But she could still talk but she would not even say give me a chamber or anything (Father2)*

A mother who was shocked by the symptoms which she suspected the patient hid for a long time hoping that they would eventually disappear regretted that she trusted the patient. Although the patient insisted that the wounds were the result of constipation, she was shocked that the patient tolerated the unsightly and seemingly uncomfortable genital ulcerations and was reluctant to seek medical treatment. In fact she was concerned that the patient was pessimistic about recovery, saying:

> *…she said to me, 'I don't think I can recover from this one'. I said what? Then she told me that she thought the tear which she had affected her genitals too. This time I insisted that she must show me. I could not believe what I saw. I said to her: 'you should see the doctor about this one and I am glad that you did not hide this one because there is nothing we can do about it only doctors can cure it'. It was many wounds... I realized that it was not going to be enough to just wipe. In the morning I helped her wash because I suspected that she had not been doing a proper job. I was not aware that she had such a serious problem and she did not say. It was bad and I felt very guilty and I felt bad but it shocked me to see that she was keeping this secret… I thank her for revealing. People hide when they have STIs. She was depressed but she is fine now and happy. I think people get embarrassed when they have STIs because people think they happen to those who do not behave well (Mother3)*

Sensitivity in bodily care

When the gender of the caregiver and the care-recipient was different, the difficulties of providing intimate care could be increased by the patients who restrained the caregivers from touching or examining their bodies, especially the genital area when bathing them. Even under extreme levels of incapacitation, the social meanings involved in body touch persisted. Some symptoms could also threaten caregiving because some caregivers were reluctant to touch the body substances which they perceived as risky or repugnant. Overall, the need to help the patients with bathing produced stress in caregiving.

Gender and resistance

A father described the frustration and conflict which ensued when his defiant daughter resisted his help with bathing despite the constraints that the family faced in terms of its age-gender composition. He felt that the patient was inconsiderate:

> *She said: "I want you to take me away from here because you are a man, I don't want to be nursed by a man because I am a girl..." Then I said but you are my child. She said how are you going to bathe me? She insisted that I should not bathe her but then I didn't know what she wanted me to do because her mother was dead and she knew that. If I had money I would hire someone... This was at the time when she could not bathe herself. Then I said: what do you expect me to do because I don't have money, your mother is not alive...? At times I requested her younger sister to help me bathe her, then after sometime I would hear a slap. She would come and say: 'she is beating me', the patient beating this girl who bathes her! She said she didn't want her sister to bathe her, she was very impossible... Sometimes I thought that she was frustrated by her lies. One day I told her: little girl, I don't know what you want, I will bathe you and I won't take your nonsense. There was a time when she refused when I bathed her... How do you explain that? Telling me that she would not be cared for by a man; that she needs a woman, but I told her that it was no use because I don't have a sister who I could ask to do this difficult work: people say they are sick, and people are busy with their own business... (Father2)*

A male patient resisted to be bathed by a female carer despite the unavailability of a willing male carer substitute in the family. She was anxious that due to incapacitation the patient could not reach all his body parts. Consequently, bathing was compromised until the time when he was too ill and could not effectively resist intrusion on his body. She was shocked when she found that he had genital infection that was beyond cure. She indignantly blamed the patient for keeping such a distressing condition to himself and was disappointed that he 'died from a curable condition' due to his mistrust of the family members. She said:

> *...this boy spent a long time not wanting me to bathe him and I told his father: "you are a man; I am worried that this boy is not bathing well because he is too weak but he refuses when I touch him". I understood because he is a man and I am a woman. And I wanted his father to bathe him...maybe he did not want to 'get it', and maybe he was afraid but he refused. Maybe some of these things that we saw late could have been discovered [earlier]. But he also did not want his father to touch him, he said he was rough, so maybe he would not even agree but his father did not even try...those things that we saw when we bathed him at a very late stage of his life could have been treated by both the doctors at the hospital and with traditional herbs* **(lipitsa)**, *it does not mean that these things are new, people have always had these diseases, gonorrhoea is not new, but if you*

> *hide it, it prunes you completely* (referring to mutilation due to severe ulceration of genitals) *and this is how this child was. I felt pain deep down, because I realized that he did not trust me or anybody in the family and he preferred to suffer alone, in silence, I just thought that he was cruel if he was able to hide such a thing but it is not easy to live with such a change especially on one's private parts, no, he was sure to die... (Grandmother)*

In other situations gender differences and feeling over-loaded could be resolved since there were willing family members who assisted because this aspect of caregiving was viewed as sensitive and demanding. The caregivers who were assisted with bathing the patients appreciated such intervention because it temporarily relieved them emotionally and physically. A few were occasionally assisted by the volunteer community caregivers who were trained by the respective hospitals to support family members who cared for chronically ill patients, who in most cases were PLWHA. But, some caregivers were reluctant to accept help with intimate care because they perceived it as private and a family matter especially when the patients' health condition had deteriorated and the need for bodily care intensified.

Caring about, sensitivity of handling bodily substances and fear of HIV infection

Apart from the depression the caregivers experienced owing to the disability and deterioration of the care-recipients, there was also apprehension that debilitation necessitated the handling of the bodily substances. Not all the caregivers were certain about the HIV/AIDS-positive status of the care-recipients, however, bathing the patients and fear of contact with their open wounds and bodily fluids such as blood and excreta tended to raise anxiety about getting the HIV infection. The caregivers who knew as well as those who suspected the HIV/AIDS positive status of the care-recipients were concerned but some caregivers were oblivious of the possible risk involved. The anxiety expressed by the caregiver below was common whenever the physical changes were observed. She stated:

> *When she could not bathe herself anymore I really wanted her to test because I took it that it would help us to talk. But at this stage it was impossible to test because she was too ill (Daughter)*

Those who knew about the HIV/AIDS diagnosis invariably practised precaution as advised by the health personnel and community health workers. Similarly, some who did not have such information but were advised by the community home-based caregivers adopted protective measures. However, the caregivers whose perceptions about the underlying cause of the illness were based on intuition and suspicion were hesitant to protect themselves but used protective materials when the patients were severely ill to actively resist such measures. Notwithstanding, it was common to experience uncertainty and fear about the risk of HIV infection in caregiving.

The risk of HIV infection was disturbing. One participant who was a caregiver of another family member became cautious as a result of her past experiences:

> *It is true I was using those 'Dettols' but I am worried that I could be having 'it' already. Maybe he has infected me. I even think that I should see them at the hospital so that they can test me. But these days I am wise., I don't just touch things that I don't know because I say, if this is what my own child could do what can I expect from outsiders. I am worried that I have 'it' because I did not protect myself when I was touching all that stuff and bathing him… How would I use them because I knew nothing and no one gave me the gloves, not even the nurse at the hospital? I did not know anything and there was no one saying anything to me. Besides I did not know much about AIDS... (Grandmother)*

Another caregiver said that she was in a dilemma because she intended to protect herself but did not want to hurt the care-recipient:

> *Just like the gloves, I asked a nurse who I met on our way out of the hospital; I just asked her informally if I could have gloves because I could see that I was heading for even more serious work and she gave me. They had not given me…I could see that she did not really like it when I used the gloves at first. I did not even wear them all the time, like what they do at the hospital, I only wear them when I do her laundry or clean her chamber not all the time or when I apply (sores) on her back. I told myself that I should have courage... the blisters were going round her chest and back, and I would not use my bare hands when I apply the medicine on the back. I wanted her to recover fast and cleaning those blisters was necessary. I used them but I was very uneasy… (Daughter)*

A caregiver, who was frustrated by the patient's secrecy, was adamant that she would not risk her life but did not also want to generate conflict in the family by adopting care measures that would be associated with HIV/AIDS.

> *Well, in the case of Ma-Lucky, there is no way I can just handle her, my caregiving cannot be that intimate, well when I am in the house and she needs to turn the side, I will help, and this is because she still has her clothes on and I am always careful that I don't have any open wounds. That's the difference... Even this morning I was still here before I went to work, I came so that I could help her daughter to change her bedclothes because it has to be done daily and many times during the day and I still want to help but will not risk my life when I know that the message is that we should all be*

> *careful, but she wouldn't say to me: "my sister, you know I think this and this about my illness..." (Sister-in-law3)*

Differently, one of the participants who provided care to a patient who was open about the illness indicated that although she was highly cautious she always worried about being infected:

> *I was helped by my fear. I was scared to hear that she has this disease; I told myself that I was going to be extra careful...She had once more developed blisters that look like chicken-pox, her ears were oozing and she had wounds that would not heal on her body...these sores also caused me problems because I feared to touch her even though I'll still be wearing gloves... It was becoming more and more difficult to handle her and help her even with the gloves. I tended to forget when I touched her that I had gloves covering my hands; my body would just shrink with fear. I was afraid. I do laundry for people and most of the time I have minor wounds on my hands so I had to be extra careful all the time. The other problem was when she had her period while ill, but that happened only when she fell ill for the first time, thereafter her period stopped. I had to wash her and her underwear, this happened for two months and it was a torture to me because it was blood. This was a serious problem for me (Aunt)*

An HIV-seropositive caregiver was equally anxious to touch bodily substances which she believed would expose her to further infection. The patient lost vitality unexpectedly and became dependent before she considered seeking protective materials from the hospital. She would not neglect the patient but she remained apprehensive since she did not use gloves and sufficient disinfectants yet she believed they were necessary.

> *I bathed him; he had diarrhoea which did not stop. It took him one week and that was the very last week of his life. It was very heavy for me because this idea of gloves was not yet common, I did not have them at all, and I did not have anything that I could use to help him, aprons or gloves. It was difficult because already we were struggling; people who do not have soap and these things that people use such as JIK. We were really suffering. And I knew that he was infected. I knew that handling him like that was not right but I counselled myself that may be it didn't matter because I was already infected. But it was causing me serious tension because there were things which I was clear I was not supposed to be just touching like that because I might increase my infection, but I had no choice because I would not just leave him in that mess, it would not be right. And I felt bad because my intention was to help him without any reservations, with all my heart... (Spouse2).*

Another caregiver knew that she had to protect herself from being infected by HIV and AIDS hence used gloves or plastic bags to cover her hands, but she tried to balance her safety with rationality by covering her hands only when she handled areas that would expose her to risk. She explained:

> *We're aware that we needed gloves but we just bathe her. It is only when we clean her wound that we covered our hands with a plastic bag. She has a wound that does not heal on her foot, it needs to be cleaned everyday and I don't know what caused it...I just told myself that I would not get 'it' if I*

> *don't touch the wound – the blood or pus from the wound. So I just bath her. I was confused at the beginning because I saw the nurses wearing gloves whenever they needed to hold her or touch her even when they made her bed... gloves, gloves all the time* [she giggles – I sensed cynicism], *so I was a little bid confused. Seriously, I was confused. In fact I was nervous at the beginning, but then my senses came back...Since they gave her a box of gloves I don't have problems anymore because with the plastic I could not be sure may be there is a hole which I did not see. Also the sounds that it makes, it is big and does not fit well, it was slippery and messy. But I'm ok now.* [Laughing]... *I told myself that I don't have to cover my hands every time when I bathe the patient; it is quite difficult for me because it is like I have to have this on my mind all the time – that I am nursing an AIDS patient and not my sister. That's why I decided I would only use them when I clean the wound (Sibling)*

Disgust

When the patients' health condition deteriorated it was imperative to help them with every aspect of bodily care. Some caregivers were challenged by handling the bodily substances which they found repugnant. They managed this feeling discreetly in their interaction with the care-recipients because they did not intend to hurt them. They feared that the care-recipients would misinterpret their behaviour as unwillingness to provide care. Although they could overcome the feelings overtime, they were unavoidable and triggered by unpleasant odour and sight of excreta and vomit which some felt less prepared to handle even though they were not reluctant caregivers.

> *At the beginning I was fearful and I felt disgusted and not willing to handle such things as faeces or when she had vomited. I just did not like that stuff. No! I think at that time I did not understand well what was happening and the kind of problem she had. I was naïve I think... Now when she cannot go to the toilet outside I take the bucket and empty it outside. I don't even think about it anymore... Even at the hospital, when I got there and found her in a mess, I clean her and wipe her so that she is always tidy. Or if she vomited, I just take her clothes to the bathroom in the hospital and clean them. I do the same here at home, it doesn't matter what has soiled them, and I just wash them these days (Sibling)*

Another frustrated caregiver said:

> *Sometimes I feel repulsion or nausea due to some odour which make me uncomfortable. There was a time when he lay in bed for a long time and it was affecting his kidneys because he was taking out smelly thick urine. It smelled terrible, and everyday when I had to clean the bucket that he used because he could not go the toilet, I felt nauseous. I had to clean the bucket there was nothing I could do, but my heart felt this irritation, well after sometime that irritation has disappeared. I made sure that when I take out that bucket to the toilet I face the other direction because it smelled bad, but I made sure that he does not see me. He would feel bad. It happens and it is part of being a human being. You cannot avoid feeling afraid or disgusted but I suppress them so that he does not recognize it (Sister-in-law1).*

The caregivers encountered myriad challenges due to the patients' deterioration in health and loss of functionality. The preceding analysis illustrates that the bodies of the patients remained the focus of care and the source of stress in caregiving. The caregivers nurtured the care-recipients and paid attention to both their physical and psychosocial needs. However, as the disease progressed and care became increasingly challenging, they primarily focused on the physical needs through care of the body. The caregiving activities were oriented towards ameliorating the observed changes in physical appearance and incapacitation of the patients' bodies. The corporeal changes resulting from protracted illness were significant because they led to the expansion of the caregiving workload and also produced intense emotional experiences for the caregivers as they strove to make the care-recipients receptive and responsive to care. Therefore, the major techniques of care in this domain were food to nourish, bathing and touching for the purpose of soothing and relieving the bodies of discomfort and empathy. Ironically, a significant level of the experienced stress emanated from feeding and bathing the care-recipients yet for some caregivers these were the only forms of intervention available and did not have alternative mechanisms through which they could meet the perceived limitations and needs of the care-recipients. These activities and their perceptions of the bodies of the cared-for profoundly affected the caregivers' experiences and evoked emotions which necessarily endangered or diminished care. Primarily, they experienced stress because there tended to be disparity between their expectations, the behaviour of the care-recipients and the outcomes of caregiving. For example, depression and frustration among the caregivers were produced by what appeared to be the evidence of the workings of the illness through the patients' bodies and their responses to care. The intricacies of bathing the patients were not confined to increased workload; they also emerged from the fact that the otherness of the patients' bodies did not suddenly vanish in caregiving contexts. Their experiences illustrate that while they 'shared' in the suffering of the care-recipients, they also shouldered substantial responsibility in the care process. They suffered stress as a result of the bodily changes which occurred despite their care efforts, contact with the sick bodies and the substances they emitted, as well as the care-recipients' seemingly uncooperative behaviour.

Discussion

The preceding analysis takes the body as a phenomenon and the idea that care is a process based on relatedness as its starting point. It illustrates that caregiving focused on the care-recipients' bodies whose responsiveness to care had mutual consequences in caregiving relationships and the caregivers' experiences largely emanated from their perceptions of the state of the patients' bodies. They observed the bodily changes which mainly signalled the care-recipients' suffering and the effects of the illness and reacted emotionally and practically. Their actions were oriented towards ameliorating and halting the symptoms and debilitation which they dreaded because they associated with death.

The experiences of caregivers as they interacted with the bodies of the care-recipients could be explained through the theoretical work on the body provided by various writers including Turner (1984, 2003), Frank (1991) and Synnott (1993), the notion of the ethic of care (Noddings, 1984; Tronto, 1993; Kuhse, 1997; Bowden, 1997; Sevenhuijsen, 2003) and the empirical work on caring for the body (Twigg, 1999; Lawton, 1998; Kelly and Field, 1996). The analysis of the bodily changes from the caregivers' perspective provided an angle from which those who support ill relatives through care might experience the ill bodies physically and emotionally. Disease affects the body and care primarily involves paying attention to individuals as embodied. The sociology of the body has been identified as entailing the phenomenology of the body – the way we experience and know our own bodies and the way we experience and perceive the bodies of others. It is essential to consider that in chronic illness disease transforms the body in profound ways including loss of control over the bodily processes thus transgressing social norms and posing threat to orderliness.

Turner's theoretical framework delineates the four tasks of bodies in society as *reproduction* and *regulation* of populations on the one hand and *restraint* and *representation* of individual bodies on the other (Turner 1984 cited in Frank, 1991). Caregiving required the caregivers to come head-on with the disease dynamics as they manifested through various bodily processes including incapacitation, food consumption, and conditions which allowed emission of bodily fluids, especially blood; and unpredictable bowel movement such as diarrhoea and incontinence. The concern with curbing these bodily changes led to the care of the body being a dominant feature of the caregiving activities and the caregivers attended to these changes using food and baths. Their actions draw attention to the centrality of the corporeality in caregiving thus showing that the effects of chronic illness on the body had profound consequences for those who provided care. Kelly and Field (1996: 247) argue that informal caregivers have to manage various physical constraints created by chronic illness and this involves coping with the bodies. Of significance to the studied caregiving experiences are the internal restraint and external tasks of bodies which Frank argues represent "the body's own problems of its embodiment within a social context" (Frank, 1991: 48). According to Frank, the significance of Turner's model lies in the realisation that the relationship between the body and society is reciprocal: "What we have in Turner's categories are not only four tasks which a society must solve with regard to bodies, but also four problems which a body must solve to be in society" (Frank, 1991: 45). The caregivers had to cope with the challenges to embodiment as faced by the chronically ill care-recipients. For example, chronic illness destabilized the learned corporeal practices or bodily techniques which helped to maintain orderliness, create and provide place for a body in everyday life (Turner 2000, cited in Weinberg and Williams, 2005: 315).

The caregivers were estranged by the extreme weight loss which changed the features of the care-recipients, defaced them and exposed the internal features of their bodies. Firstly, they reported that daily contact with the patients' bodies was distressing. They were concerned about the disfigurement of the bodies which they perceived to be linked to the effects of a disease which was 'finishing the patients'. For instance, they were concerned about incapacitation, severe genital infections involving mutilation of organs, skin ulceration and odour due incontinence. The caregivers' emotional experiences in this regard suggested that these corporeal challenges exceeded their past experiences and competences in terms of rate and degree of deterioration, therefore, they were overwhelmed. The changes in physical appearance due to the AIDS-related illnesses are widely documented[3]. Furthermore, Persson (2004) notes several bodily conditions associated with AIDS which include extreme loss of weight. She suggests that HIV and AIDS illness typically alters or disfigures the body

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[3] Asha Persson (2004) notes that deficiency in immunity as a result of HIV infection is associated with several viral, fungal and bacterial infections, what have become known as opportunistic infections, which affect different parts of the body both internally and externally causing lesions to respiratory and digestive systems, on the skin and structurally.

conspicuously and highlights that one of the known bodily signs of AIDS where there are no antiretroviral therapies is "HIV-related wasting". This study contributed understanding on how lay carers experienced these changes including their implications for care. In a situation where anti-retroviral therapies were not available and household food insecurity a major problem, incapacitation and wasting were inevitable. In this way HIV and AIDS has indisputably revived the significance of the body not only in social theory (Turner, 1991; 2003) but also as a rich source from which the presence of disease could be read from the exterior of the body by lay people (Lupton, 2003). This situation explains why public health attempts to maintain confidentiality and discourage stigmatisation of HIV and AIDS by insisting that clinical blood tests were the only way to know about others' sero status seemed to create widespread suspicion and ambiguity around chronic illness and home-based care.

Those who provide care manage such bodily changes in relationships that should ideally protect the interests of both parties; in fact this happens in formal care settings. Difficulty in balancing these interests and realising care goals rendered the bodies a multifaceted source of stress for most caregivers. The bodies were not only a symbol of expressed and discerned suffering; they could also resist care or fail to show improvements which matched care efforts. Given that HIV is a volatile infection with the capacity to affect all the bodily systems, taking care of the bodies was bound to be challenging. Aspects of the care environment such as lack of access to ARVs and severe symptoms produced care challenges which evoked poignant emotions. This situation was exacerbated by the caregivers' limited access to information regarding the prognosis of the illness. But, in some instances care was threatened and diminished by the care-recipients who resisted care. The idea emphasised in the nurturance framework that care is based on relatedness characterised by interdependence between the parties involved in this process (Duffy, 2005) and articulated through the ethic of care was undermined by what seemed to be the care-recipients' resolute concern to maintain confidentiality about their HIV/AIDS status irrespective of loss of independence. Care theorists (Noddings, 1984; Tronto, 1993; Kuhse, 1997; Bowden, 1997; Sevenhuijsen, 2003) emphasize that interdependence entails the carer taking responsibility and the cared-for being responsive to care. Inability to protect own interests created anger and dilemmas in caregiving.

Some of the implications of the bodily changes for caregiving were that caregiving tasks and responsibilities expanded and intensified thus producing a fertile environment for stress. They also meant consistent engrossment with the patients and attentiveness to their needs. Consequently, incapacitation was a dreaded condition and some caregivers who had previously experienced the situation whereby the patients depended entirely on them for personal care strove to prevent it from recurring. Despite their efforts, severe illness could still lead to high levels of disability and loss of competence over corporeal practices leading to increased dependence on the caregivers. For example, severe illness constrained the care-recipients from bathing, eaten or toileting independently. Pearlin, Aneshensel and LeBlanc (1997) hypothesise that in AIDS caregiving it is inevitable that caregivers will experience stress proliferation as a result of the demands of the care-recipients increasing due to declined capacities as the disease progressed. Similarly, incapacitation led to marked loss of social status by the care-recipients and was also distressing because essentially, it introduced pessimism since it implied that the illness had taken an irreparable course. Consequently, those who experienced incapacitation were hopeless while ability to maintain bodily integrity was interpreted positively to signal possible recovery.

Secondly, depending on the degree of incapacitation, caregiving entailed helping with personal bodily care. Consequently, bathing was a crucial care technique for maintaining dignity which was relevant for the ill individuals and the rest of the family members who could also experience 'stigma by association' and criticism because of poor care. Necessarily intervention was made when the caregivers assessed the changes as requiring them to intensify their help, but they generally avoided intrusive care to encourage independent functioning and protect the self-esteem of the patients. Perhaps this was because 'taking over' could inadvertently threaten the dignity of the cared-for. Chochinov, Hack, McClement, Kristjanson and Harlos (2002: 435) observe that "loss of independence or functional capacity resulted in a corresponding fracturing of the patients' sense of dignity". As a result, they observed the decline in the patients' capacity to provide their own intimate care and intervened when they perceived it necessary. Tronto (1993) indicates that '*taking care of*' as a phase in the caring process entails agency and taking responsibility. This is one aspect of care according to the nurturance perspective which the moral theorists identify as "feelings of affection and responsibility combined with actions that provide responsively for an individual's personal needs or well-being, in a face-to-face relationship" (Cancian and Oliker quoted in Duffy, 2005: 68-69). This orientation sustained care even though in situations where the care-recipients perceived it as invading their privacy, such intervention could also threaten care. Inevitably, incapacitation meant that the caregivers disregarded the cultural conventions of body touch (Synnott, 1993; see Willis and Dodds, 1998 on touch as a reproductive strategy) for the sake of care.

The degree to which help with bathing required the caregivers to intimately touch the patients' bodies differed according to the patients' degree of incapacitation. Twigg (1999) observes that the onset of disability and the need to provide care through bathing disrupts the privacy inherent in the spatial ordering of the body. Generally, the caregivers would not wash the patients' private parts unless they perceived it absolutely necessary. This finding corroborates Twigg's (1999) assertion that the care-workers promoted independence by allowing the care-recipients to wash their private parts because this aspect of care was generally awkward. This approach could be viewed as an indication that to a large extent, the caregivers recognized that caregiving had to be in accordance with the needs and the perspectives of the care-recipients (Sevenhuijsen, 2003) but when they perceived it critical to bathe the patients, they ignored the emotions of the cared-for and emphasized physical care.

Consequently, despite its importance, bathing the care-recipients was demanding emotionally and physically. For instance, although vigilant, the caregivers missed some of the conditions which needed care and medical attention; the genital infections which they dealt with were shocking yet taboo. They usually suspected that the cared-for hid these severe conditions because they feared that they had meanings which could potentially tarnish self-image. Persson (2004: 62) comments that for fear of stigma, a visible condition such as lipodystrophy[4] was "enveloped by silence and avoidance...swept under the social carpet, [and] largely consigned as an individual problem rather than a collective or political concern..." Similarly, it may be argued that while public health warns about the vulnerability introduced by sexually transmitted infections in contracting HIV, the caregivers were not aware of the severity of these conditions among the AIDS patients. Since they were not

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[4] An unusual process of fat redistribution identified as one of the common side effects of antiretroviral therapies among HIV positive individuals giving conspicuous features such as bloated abdomen, flat bottom, stick-like arms and legs, extremely enlarged breasts, a mound of fat lodged at the back of the neck, extremely sunken cheek, etc. (Persson, 2004:52)

empowered to be vigilant, as such, they depended on the cared-for to articulate the symptoms and cooperate with them.

Moreover, the degree of incapacitation experienced suggested that it would be impossible to balance the justice principles such as autonomy with care. Especially in a situation where health care services did not include provision of effective medical treatment to prevent disability, upholding values which did not recognise the patients' dependence was ironic. Undeniably, touch is embedded in social meanings which vary according to relationships and contexts; bathing the patients contravened some of these basic rules of behaviour about access to bodies whose owners had concretized a sense of self and would ordinarily limit such access. For instance, parents may see boundaries of touch being firmly configured during their children's puberty "as youngsters assert their right to privacy, and to control the maintenance of their own bodies" (Synnott, 1993:174). Bathing adults interfered with the care-recipients' privacy, a value which is usually discussed in the context of autonomy as it applies to the provision of adult care. In fact, various writers emphasize that illness and related incapacity directly indicate that, in varying ways, human existence is inherently based on dependency and vulnerability (Bowden, 1997; Sevenhuijsen, 2003; Tronto, 1993). It is therefore ironical that contemporary societies emphasize autonomy and overlook the "contingency and vulnerability of human life" (Bowden, 1997: 103) which people face from time to time due to illness. Theorization on access to others' different body parts suggests that while touching is highly tabooed (Twigg, 1999; Synnott, 1993), it is usually unproblematic in care contexts. But, in this study, the barriers seemed to be erected as part of the care-recipients' strategy to manage disclosure of the symptoms which were likely to generate stigmatisation.

Furthermore, these experiences suggest that gender and age differences between the caregivers and the cared-for could override family relationships and the critical need for care. The felt inhibition by the caregivers and resistance of the care-recipients when the touching of bodies was involved suggested that age and gender mismatch between the two parties could affect care negatively. These experiences make sense when considering that even in professional care relationships the ability to view the body 'neutrally' is acquired through a process that entails socialisation into the caring roles. Lawler (1998) indicated that bathing the patients challenged newly-trained female nurses who encountered embarrassment when they saw and touched naked bodies of male patients, and they developed courage and competence in sponging the patients after periods of awkwardness in these situations. These challenges are attributed to the British culture which is predominantly non-tactile. Most contemporary cultures recognise body boundaries of varying degrees, but the matter is hardly acknowledged when informal caregiving is discussed.

In particular, most male and elderly caregivers in the study considered themselves as incompetent and their involvement as an anomaly. The unavailability of female carers in their households due to the death of women who would have otherwise provided care compelled them to assume the role yet they perceived themselves as lacking patience and other virtues which they associated with women, especially when the care situations were difficult. Since their self-conception suggested a poor sense of mastery in the role, male and elderly caregivers were likely to experience more stress than younger female caregivers. Pearlin, Aneshensel and LeBlanc (1997: 230) suggest that in caregiving "the feeling that demands overload one's capacities and an ensuing sense of being an involuntary incumbent of the caregiver role are stressors in their own right..." Also, in a culture where social relationships tend to be predominantly influenced by authority, these findings may suggest that the adult children who provided intimate personal care for parents also experienced role strain. The idea that in human interaction, tactility is not gender neutral and has a power basis (Synnott, 1993) may not be ignored when attempting to unravel the sources of stress in caregiving. Mortality due to the HIV and AIDS epidemic has profoundly altered the family structure in Lesotho thus leading to individuals performing the caregiving role though it did not ordinarily fall within their domain.

Thirdly, bodily care produced stress because of the disorderliness which arose from the bodies' inability to control bodily processes and contain its matter in a predictable way. Apart from increased workload, this change also led to stress because it created a situation whereby the caregivers had to confront substances such as bodily waste and body fluids which are ordinarily dealt with privately. For instance, inability to toilet in socially designated places due to incapacitation, bouts of diarrhoea, urinary incontinence, blood as well as skin infections which secreted fluids were some of the challenges in caregiving. Evidence also suggested that the cared-for could be embarrassed by moments of bodily spillage. Turner,

(2003) and Weinberg and Williams (2005) suggest that there is uneasiness that is created by bodies when they behave unpredictably and allow internal substances to escape in the presence of others. It would seem that in the context of chronic care by family members, the family caregivers equally share in the burden created by unpredictable bodies and this may be part of associational stigma. It has been suggested that matters pertaining to defecation are a factor that can significantly contribute to family members experiencing distress in managing chronic illness. Gray (1994) established that for the parents of autistic children, the degree of a child's disability as measured by its general social consequences instead of the rate of recurrence of symptoms was more important in the experience of stress. The finding that the caregivers were uncomfortable with bodily excreta is also substantiated by evidence from cancer care contexts whereby the onset of 'unboundedness' was found to be an important factor which triggered seeking hospice care among family carers (Lawton, 1998). Dealing with odour and the sight of some of the bodily substances required great effort, and adjustment occurred after periods of uneasiness.

The additional burden to the caregivers may be due to the widespread notion that 'leaking bodies' (Seymour, 1998) and "fluids that pour or seep from the body" are risky because they contaminate; "we fear the fluid debris from other bodies as the conduit of infection, disease and destruction" (Turner, 2003: 3). The bodily matters were more concerning because they posed a risk of contamination which could lead to death. The stress emanated from the knowledge or suspicion that the bodily fluids posed danger of HIV infection. The negative emotions such as disgust and fear which people experience towards "human bodily wastes…in modern societies are closely tied to the maintenance…of boundaries between those elements categorized as 'natural' and 'cultural'; it is inextricably linked with both flows and barriers between the stuff of each" (Smith and Davidson, 2006:48). Turner (2003: 5) summarizes the social threat of such fluids thus: "the fluids that flow from inside of bodies to the outside are dangerous and contaminating because fluids on the outside of our bodies challenge our sense of order and orderliness". Similarly, Douglas (1966) argued that both western and non-western societies were equally concerned with creating orderliness and as such had devised ways of categorising their worlds into contaminating and pure. Their emotions suggested their concern with infection, but also that dirt was matter found inappropriate in a given place (Douglas, 1966). The values regarding maintaining autonomy and self-control as defining traits of individuals (Crawford, 1994) persisted in caregiving with the caregivers taking over the responsibility to maintain boundaries even with the outside world.

The view that in non-western cultural settings bodily substances may be tolerated because "persons are not thought of as having authentic identity mapped onto a singular body" (Lawton, 1998: 137) is a misconception. It does not seem to take into account the spatial reorganization regarding the management of human waste which includes rural sanitation; and which has led to the exclusion of such bodily matters from daily social experiences in most of these societies. The caregivers' sensitivity to managing the home environment where care took place by controlling odour; sanitizing bed clothes and the body – while sometimes disregarding the emotions of the patients – pointed to the cultural significance of managing waste. They also considered the consequences of taking the patients into public spaces such as public transport when they had diarrhoea.

Fourthly, since care implied responding to others' inadequacies and repairing what was amiss to maintain life (Tronto, 1993), the caregivers' reactions in relation to the observed physical changes were unavoidable. The stress which ensued could be understood from the perspective that caregiving was outcome-oriented. This assertion is consistent with what is considered to be the defining feature of helping behaviour based on altruism. The caregivers oriented their actions towards specific bodily conditions of the patients; both existing and anticipated, and they assumed considerable responsibility for things which happened about the care process and outcomes. Obviously, inability to thwart weight loss and incapacitation produced stress. In a study on stressors and problem solving, Thoits (1994) directed attention to results of problem-solving endeavours and highlighted the agency of individuals who face difficult situations. Thoits concludes that in the domains studied – work and marriage/love – stressors arise because among others, "the *outcomes* of problem-solving attempts are unsuccessful", while "effective problem-solving efforts reduce difficulties in a role domain" (p. 147; p. 148). It was understandable that the caregivers would develop stress when they could not meaningfully ameliorate the care-recipients' suffering. The inability of the society to make ARVs available led to a situation where the bodies were affected by severe opportunistic infections, debilitation and extreme loss of body mass which shocked and alienated those who maintained close contact with the patients by providing personal care.

Fifthly, the poignant experiences were produced by the non-cooperative behaviour of the cared-for in relation to food consumption and which was associated with failure to halt debilitation. The caregivers regarded food as crucial in preventing loss of vitality and energy, which could eventually lead to the patients being bound to their beds, complementing medication and counteracting the illness. Their narratives highlighted their perception concerning the significance of food in caregiving. For example, they ensured that the cared-for ate food and they had negative experiences when eating was disrupted. Depending on what seemed to work, they persuaded, forced or helped the care-recipients to adhere to preferred eating patterns. Therefore, they experienced anxiety when the care-recipients could not eat and derived pleasure when they conformed. Their actions in this realm were guided by their ethical, cultural and subjective understanding of how they should help the patients and the changes in the bodies associated with food consumption. Mintz and Du Bois (2002) indicate that anthropological studies in relation to food and eating have specified different aspects of social life including symbolic value creation. Mepham (1996: xi) contends that food is so basic to human existence that "it readily becomes the focus or means of expression of a whole range of other human concerns, both beneficent and maleficent". McInerney (1992) highlights the symbolic significance of feeding terminally ill patients and how this concern may surpass reason.

Accordingly, there were two factors which displeased the caregivers. The caregivers became worried when the cared-for could not eat food or stopped eating since this behaviour was perceived as signalling death. Similarly, involuntary conditions such as vomiting and diarrhoea were upsetting and induced stress because they counteracted the effort to nourish the body. The care-recipients' poor eating tendencies contradicted the caregivers' own meanings of care as embedded in the culture: serving others food to show association and compassion. The strong link between food and survival has generally been recognized (Telfer, 1996). In some situations the patients did not have medication, so consuming food was essential because it was the only substance put into the body to hold life and express care. Dower (1996) recognizes that in the presence of disease and illness, hunger may trigger early death and therefore as part of benevolence, caring must prevent suffering brought by hunger. Therefore, it would be uncaring to deny the weak patients food.

Additionally, the caregivers' stress in this domain emanated from the way they perceived the care-recipients' bodily responses to care. Food consumption was also emphasised because it was believed to affect bodily appearance positively, however, how bodies actually responded was beyond the caregivers' control. The care-recipients who ate accordingly were expected to recuperate and they raised hope about recovery. McInerney (1992) illustrated that even in terminal illness, family members noted otherwise insignificant physical changes such as weight gain by patients and pointed out that these experiences were evidence that feeding had emotional impact. The fact that there was lack of congruence between caregiving efforts and bodily changes produced profound emotional consequences in caregiving. For example, wasting was distressing because in some situations it continued despite efforts to feed the patients while sometimes it happened even though the patients ate satisfactorily; and some of the poignant and paradoxical experiences were when the patients died while they ate satisfactorily and sometimes had gained weight. Optimistic expectations about bodily responses could be exacerbated by lack of information about the prognosis of illness and unawareness of the extreme debilitating effects of the HIV/AIDS disease, and its ability to hamper the optimal benefits of food consumption and produce extraordinary nutritional deficiencies. They were not adequately informed about these physiological processes even though in poor countries HIV/AIDS has been strongly linked with adult malnutrition outside the conventionally vulnerable groups such as lactating and pregnant women (Young, 2001). This condition is recognized as one of those which undermine resistance to opportunistic infections, making recovery from disease difficult and accelerating incapacitation. This explains why food and nutrition are recognised as integral to most programming in HIV/AIDS intervention (Strasser, Egge, Huddle and Greenaway, 2005), especially in Southern Africa since 2002 when the food crisis hit the region.

In summary, the fact that the care-recipients, asserted their desire to maintain autonomy by refusing food as well as privacy by tacitly or openly resisting the help with bathing was ironic and frustrating to the caregivers who encountered the behaviour. The caregivers viewed the behaviour negatively and thought that the care-recipients did not appreciate care. Given the philosophical and ideological meanings of care, a reasonable expectation would be that those who need care would not resist it but would be available for it because they were vulnerable. But as Mol and Law (2004) remarked, the living bodies are both object and subject in that they constitute what they *have* and what they *are*, respectively. Since the care-recipients were economically and physically active prior to incapacitation; they were likely to embody a self-image which did not match their abilities as affected by the illness thus creating stress for the caregivers who expected them to be receptive of care. These findings highlight the idea that care is based on relatedness. The care theorists have rightly indicated that independence and autonomy in caring relationships are absurd. That is, when some of the care-recipients refused food, hid severe symptoms and rejected help with bathing, the caregivers became frustrated. Lack of responsiveness to care by some of the care-recipients threatened caregiving as it was apparent from some of the harsh measures which some of the caregivers adopted. Such responses also suggested poor adjustment to the role which is a problem that Noddings (1984) raises; that the attitude of the cared-for contributes to the care relationship and may be blamed for the ethical deterioration of the one-caring. Noddings (1984: 48) emphasizes,

> Clearly, the cared-for depends on the one-caring. But the one-caring is also oddly dependent upon the cared-for. If the demands of the cared-for become too great or if they are delivered ungraciously, the one-caring may become resentful and, pushed hard enough, may withdraw her caring. Each of us is dependent upon the other in caring and moral relationships. The very goodness I seek, the perfection of the ethical self is, thus, partly dependent on you, the other.

The caregivers' experiences showed unequivocally that care entailed emotions and interdependence between the caregivers and the care-recipients – "feelings, responsibility, responsive action, and relationship" (Duffy, 2005: 69).

The finding that most of the caregivers prioritised the welfare of the care-recipients even when they were concerned about contamination, including fatal infection, is important. It illustrates that once family caregivers assumed the responsibility they did not relinquish it. The behaviour of the caregivers in the studied kin-based caregiving relationships may be viewed as altruistic. Piliavin and Charng (1990: 30) define altruism as "behaviour costly to the actor involving other-regarding sentiments; if an act is or appears to be motivated mainly out of a consideration of another's needs rather than one's own". They argue that in situations where empathy is experienced actors will be motivated by altruism to contribute towards alleviating the victim's predicament.

This analysis demonstrated that the care-recipients corporeality were central to the consciousness of the caregivers who strove to ameliorate the effects of the disease on the body through physical care. Ironically, the bodies were a rich source of stress because in most cases they resisted care voluntarily and involuntarily. Feeding and bathing the patients were stressful to the caregivers because they were met with resistance from the care-recipients who would sometimes refused food or would not allow the caregivers to touch their bodies; probably to maintain dignity, autonomy and privacy. Incongruence between the caregivers' and care-recipients' interests were bound to strain relations and create stress. Extreme bodily deterioration was inevitable because the caregivers did not have access to antiretroviral treatments and many households depended on food parcels which included items that some patients found unappetizing. The experiences of the caregivers with the bodies of the care-recipients illustrate that the care context as characterised by lack of ARVs produced bodies from which it was easy to discern the presence of disease and suffering. However, confidentiality concerning diagnosis and prognosis of illness meant that in many situations the conditions were inexplicable. Of significance also was the challenge posed by touching these bodies which aroused strong emotional responses from the caregivers who touched and observed them daily, as well as the substances which they loathed or perceived as risky. The HIV/AIDS epidemic was partly responsible for the unavailability of suitable caregivers, especially women who could play the traditional gender role of informal caregiving. The situation has produced categories of 'unconventional' carers who felt comparatively incompetent for the role.

CHAPTER EIGHT

CONCLUSIONS

The study investigated the experiences of family caregivers who cared for chronically ill family members diagnosed with HIV and AIDS at home. The intention was to obtain experiential evidence from the people who had experienced caregiving in the era of HIV and AIDS but before the ARVs were introduced through public financing in Lesotho. The data obtained through the phenomenological approach show that it was fruitful to avoid the use of the various lay and scientific constructs as a framework for the conversation with the caregivers. The use of *epoché* or 'bracketing' generated meanings which were relevant to the caregivers in their situations. Constructs such as caregiving, caring for the patient's body, caregiver burden, access to health care and confidentiality have been widely used in the study of HIV and AIDS care but with little attempt to illustrate how they may appear to the consciousness of those who have first-hand experience in the care of patients outside the formal medical settings.

The point of departure and critical for caregiving to happen was the emotional response that led to a decision to help the patients recover. Caregiving occurred as a result of the emotional responses of these individuals to the situation of their relatives whose illness they became aware of and perceived as life-threatening or limiting their capacity to improve their health condition or carry out the activities of daily living on their own. It was a response by relatives who willingly assumed the responsibility to support the patients by providing them with companionship, assist them to obtain and use medical treatment as well as perform tasks with and for them without taking into account the length of time such help would be rendered. The process entailed actions meant to ameliorate the patients' suffering by attending to their needs while suspending own interests. Caregiving was implemented by first, ensuring the proximity of the carer to the sick person by relocating, second, initiating relationships and processes which were intended to reduce the perceived suffering and maintain the life of the patients. Third, they used commonsense, emotions and hands to alleviate the care-recipients' physical and emotional discomfort while also expecting 'help' from them.

The caregivers shouldered the bulk of the responsibility of ensuring the wellbeing of the patients at home but also envisaged a supporting relationship with the health care institutions. The quantity and quality of such connections affected caregiving experiences because they influenced the extent to which the caregivers could access medical care for the patients. Since caregiving was a goal-oriented endeavour, outcomes permeated the caregivers' experiences: the difficulties which ensued in the process of caregiving including poor communication with the health care providers and the patients as well as life-threatening symptoms aroused painful emotions and increased the amount of care tasks performed thus producing stress. However, the problems encountered did not lead to the termination of the care relationships between the caregivers and the care-recipients. Similarly, Chimwaza and Watkins (2004) found that the process of care remained patient-focused irrespective of whether family caregivers were aware of AIDS or not.

Caregiving was depicted as both emotionally and physically demanding. Poignant experiences were pervasive mainly because the predominant elements of caregiving experiences were chaos, stress, secrecy, doubt and suspicion; ineffective and difficult to obtain medicines, life-threatening symptoms, dealing with unbearable bodies and bodily substances, unappreciative patients, being alone without the expected support from the hospitals in the form of hospitalisation of the patients when it was necessary and helping to solve the riddle around the symptoms. From the beginning, the response patterns of most caregivers resembled those usually characteristic of emergency situations. Even though they provided care for individuals with chronic illnesses, they responded to urgent situations and in many cases the disorderliness persisted, thus producing stress and burden. Calm moments in caregiving were rare and perceived as transient and illusory.

Social theorising has formulated care as integral to maintaining life and social reproduction in society. The most useful theoretical and empirical work is provided by the feminist scholars who have unambiguously illustrated that care is a matter of human relationships, emotions and doing things for others who may be constrained by age and physical wellbeing. It is intrinsic to maintaining human societies and social life, yet care work is usually relegated to the periphery by first shifting it into the hands of powerless groups. Second, societies do not usually commit substantial resources to the areas of life which are supported through care. Furthermore, the scholarship highlights that care is a social responsibility, but its locus is largely the prerogative of governments which determine from time to time how the responsibility of providing care may be shared in society. Defining the boundaries of care is important because this activity has resource implications for families and the state. The literature recognises that deinstitutionalisation as a policy framework shifts care to the private domain with families, especially women, assuming the bulk of this responsibility.

Although research has paid attention to the experiences of those who provide care to chronically ill family and non-family members, few studies have systematically considered the relevance of the factors in the larger environment of care in describing how caregivers may experiences caregiving negatively. Perhaps this is hampered by some of the assumptions about care for the chronically ill which are part of the "natural attitude" as revealed in social policy documents and sociological literature alike. For example, the common perceptions and attitudes of the members of society towards HIV and AIDS are important, however, analysis on how stigma may affect caregiving experiences provides only part of the picture of the environment of care. Also, HIV and AIDS research resuscitated the notion of "caregiver burden" but the helpful analysis has been that which highlights the contextual factors even though the emphasis has been predominantly on AIDS stigma.

Empirical evidence from the current study showed that the contextual factors were multifaceted and they simultaneously affected the caregiving experiences. This study conceptualised care as a process and a societal practice; meaning that it was dynamic, and affected by specific contextual factors. The idea was not to discover any of them since they constituted the environment common to most members of society. But the study has documented what happened when ordinary members of society carried out caregiving responsibilities in this kind of environment and explicated their experiences within the specific conceptual formulation of care provided by Noddings (1984) and Tronto (1993) as well as the African philosophical outlook of *ubuntu*. The elements of the care environment as existed in Lesotho were juxtaposed with the principles of the two perspectives in order to highlight and describe the tensions and contradictions that emerged in individual caregiving situations.

The experiences of the caregivers in the study emerged in the context of certain health care practices by the hospitals and the social, political and economic factors which together constituted the care environment and fundamentally influenced how the process of care evolved. The important factors which affected caregiving experiences were frequent and life-threatening illness episodes, confidentiality about diagnosis which excluded the caregivers, a "minimum package of care" for the treatment of opportunistic infections, the high cost of antiretroviral drugs where available and restrictions on hospital admissions and shortened stays. The bottom-line was that the caregivers perceived this environment as peculiar in many respects. Their subjective experiences indicated what they perceived about the world of care.

The analytical framework used to explicate the "essence" of the caregivers' experiences considered the tensions that arose when home based care was practised in a society that depended on hospitals for health care for decades. The adoption of home care to deal specifically with a disease, for which confidentiality in the medical care relationship was emphasised, seemed to be contradictory. Also, the caregivers' experiences were examined taking into account that the primary but tacit concern of the planners was rationing of resources such that members of society with particular health care needs would not over-burden the health care system. The analysis also considered that there was a link between rationing and demedicalised care especially when the care discourse was dominated by views which emphasised non-medical interventions in the form of the home as the place for care, nutrition and socio-psychological support. These elements of the environment were intertwined and they produced unique caregiving experiences.

Therefore, caregiving experiences entailed the meanings which the people who provided care identified in their descriptions as constituting the "essence" of caregiving for home-based patients in the era of HIV and AIDS. These meanings emanated from their situations of caregiving, and although they were individual experiences, they were influenced by the social and structural aspects of the care environment which existed in Lesotho in the 'pre-ARVs' era. Some aspects of the care environment were found within the home sphere and included the behaviour of the care-recipients and poverty. Their behaviour before the illness advanced and when caregiving was ongoing contributed to the experiences of the caregivers

– their communication with the caregivers and behaviour, their corporeality as manifested in symptoms and the tendencies of their bodies at different stages of their illness affected the caregivers' perceptions and beliefs in caregiving. But, these were intrinsically linked to the larger context consisting of the policy, social and medical factors and institutional practices all of which had emerged and been modified as a response to the HIV and AIDS crisis. These macro factors influenced decisions about where and how the care for the patients would occur and at what cost.

Caregiving begins with taking responsibility to ameliorate the undesirable situation of someone in need of care. But starting the process of care partly depended on the patients communicating their illness to others especially those who did not normally live with them as they would not have the opportunity to observe the changes which signalled illness. Similarly, acknowledging that the observed changes were significant and warranted medical attention would facilitate early response in the form of care. The patients' behaviour when they experienced the illness contributed significantly to the caregiving experiences because it deviated from the expectations about how family members act when they experience serious illness. They did not initiate communication about their illness with the people who eventually became their caregivers until the symptoms had advanced. Some depended on other members of kin to communicate their illness when it was already critical. There was lack of agency on the part of the care-recipients as most caregivers initiated the caregiving relationship. This finding has implications for a concept such as illness behaviour which assumes that family members are usually involved in the evaluation of the symptoms and early responses to them.

There are several possible reasons for the behaviour of the patients which led to the abrupt initiation of caregiving. First, when individuals experience symptoms of a disease which they have been managing secretly, it might take time before they communicated the illness when it eventually set on. The desire to maintain the secret persisted beyond the threshold of illness which individuals would ordinarily manage without help. This behaviour was responsible for the caregivers experiencing situations whereby the patients did not have adequate care from as early as possible. In this way felt stigma prevented open communication between the patients and the relatives who nevertheless, immediately empathised when they observed their situation.

Second, delayed caregiving could also be explicated by the fact that home-based care has been resuscitated following a long period of dependence on hospitals for the care of the ill. Accordingly, the patients could easily assume that they would not have to depend on the family members for care for extended periods as they would be hospitalised when the need arose. It may not be clear how the hospital personnel communicated information pertaining to home-based care to the patients, but the patients' care plan was rarely discussed with the caregivers. Planners have identified poor VCT attendance as the obstacle to adequate planning for treatment and prevention of HIV. However, in the context of care, it was possible to diagnose HIV and AIDS when people consulted health care institutions for medical treatment hence their designation for home-based care. Failure to find means of involving "potential caregivers" to enlighten them about how the care of the patients would be implemented under various conditions, including when hospitalisation could be granted, made home-based care chaotic. This was because the caregivers unexpectedly initiated care while the symptoms were already advanced. Normally, they were not aware of the impending illness and did not know about the prognosis of the illness even though they took responsibility about the patients' situation.

Third, there is also a common view in society that illness in any form implies some degree of dependency. Similarly, the ideas about care which emerged in the 1990s when the western governments adopted deinstitutionalisation of care and espoused policies that placed care within the responsibility of informal relationships were silent about the role of the people who needed care in ensuring that care became available when it was necessary. Perhaps, this tendency had to do with the fact that deinstitutionalisation was mainly a policy response to the care needs of the elderly with chronic illnesses. Since such illnesses would be part of the aging process they would be expected at this stage. Besides, the elderly would have invested in relationships and most of them would have grown up children who would arrange care for them. The chronic illnesses brought by HIV infection defy these demographic assumptions about who are the most likely recipients of informal care in society.

Finally, by analysing care as a familial responsibility and one that may be understood within the gender division of labour framework, even critical thinking on care has neglected the role of those who receive care in facilitating it. Although inadvertent, given that the feminist scholarship was intended to emancipate the female caregiver mainly, it would seem that in advancing understanding on care work as part of the women's world, feminist research obscured the care-recipient. This is a serious shortcoming and the attempt to rectify this view emerged from the scholars who write from the perspective of disabled people. They criticise the dominant idea that care inherently entails meeting the needs of a *dependent* care-recipient. However, by viewing the non-passive role of the cared-for as 'masters' who pay the carers is also conceptually limited because only a small proportion of care work may be covered under the ambit of purely economic relationships in which the cared-for dictate the terms of their own care. This approach may also lead to care relationships being entirely commercialised yet care is one of the few social activities which maintain the physical, social and emotional wellbeing of various categories of people in society without remuneration. Such inclinations would also deprive care of its emotional dimension as it would primarily be instrumental.

There is another dimension of the care relationship which is obscured by emphasising dependency. This view oversimplifies the reality of caregiving relationships because it disregards the capability of the care-recipients to manipulate the care situation to suit their own interests some of which may be detrimental to those who provide care. For instance, concealing HIV positive status from the family caregivers who might not ordinarily be as cautious or aware as the carers in formal settings to prevent the risk of infection was incompatible with the ethic of care and *ubuntu*. This view also overlooks the possibility of the care-recipients abusing and exploiting those who provide care. These may not be common elements of a doctor-patient relationship because professionals always have the advantage of being accepted by the patients as knowledgeable, which is not the case with informal carers. Besides, the suitability of the carers for the role may be undermined by other social characteristics such as gender and age. Research on caring for the ill does not pursue the question of the caregivers who succumb to abuse by the cared-for because the presumption would be that it happens the other way. This is the situation assumed by the construct of caregiver burn-out. But it is equally important for society to acknowledge that there are situations when care may not be received appreciatively for various reasons. Such situations definitely eroded care and increased stress for the caregivers who wished to see the care-recipients cooperative. The dominant view that being a patient entails dependency on carers does not allow for the conceptualisation of care which recognises the tensions that may emerge in care relationship as a result of the care-recipients refusing to surrender their independence and autonomy. Indeed such attitudes were inconsistent with their situation: severe illness and the necessity of care.

The point is that it would be important to bring the care-recipient into the picture as someone who does not simply receive care; but one who can also contribute to their own wellbeing by showing agency and ensuring that their care is not disrupted and they have willing caregivers early. There were family members who were altruistic and prepared to provide care despite the difficulties but the challenge lay with the health care personnel and the patients to involve them. This requires a radical shift from the common assumption that individuals who receive care are a monolith group of people who necessarily constitute a "dependent" population. It would basically involve improving communication between people diagnosed with HIV and the potential caregivers. Although confidentiality was a result of the concern with AIDS stigmatising effects, the silence could also explain the unavailability of caregivers in some situations and the neglect of the patients by the members of kin who were aware of their situation but probably used it as a justification for escaping this challenging and expensive familial obligation. Caregiving is generally disruptive to life and also entails a sedentary lifestyle which is incompatible with the demands of modern life especially the participation of the traditional candidates for caregiving – women – in work outside the home.

Understandably, one of the sources of stress in caregiving was when the care-recipients' behaviour did not adapt to the efforts and goal of the caregivers to change the health condition of the care-recipients positively. This behaviour manifested in many ways including failure to be receptive of the care provided by being unappreciative or resisting care and did not accept baths, food and medication. Caregiving could also be chaotic when the patients persistently failed to respond to care or resisted it. The behaviour did not comply with the caregivers' expectations that the care-recipients would cooperate with them to find a solution to their predicament. These observations illustrate other limitations of the sick role and challenge researchers who study illness behaviour and compliance of the patients to expand their frameworks. In the context of home-based care, compliance seems to mean more than using medicines as instructed by the doctors or nurse clinicians. Given the variety of techniques that the caregivers use to ameliorate illness, compliance may also involve the patterns of use of food as well as agreeing to be bathed. In home-based care these non-medical techniques may be perceived as equally important. This study has contributed some understanding on how non-medical techniques which were perceived as critical in improving the wellbeing of the patients contributed to the experiences of caregiving. The caregivers' meanings about food and bathing influenced their experiences about the patients' behaviour; generating stress and also being sources of optimism.

Perpetuating the idea that the care-recipients were entirely dependent on others contradicts some of the fundamental characteristics of care as pointed out by the theorists of care. They categorically indicate that care involves two-way relationships, and mutual interdependence between the cared-for and the caregiver whereby one of the expectations is that the cared-for must be receptive to care. The notion of "care-receiving" as a dimension of care that is based on relationality highlights this imperative. This perspective clearly indicates that care is enhanced by the behaviour and attitudes of the cared-for including being appreciative of the care provided. Tronto's (1993) clearly delineates the four phases of care – caring about, taking care of, caregiving and care-receiving as intertwined.

Many writers have commented that the human-rights-medical principle of confidentiality is problematic in the context of HIV and AIDS and the family in Africa because this principle is inconsistent with the collective response to illness in terms of its interpretation, its causes and identification of treatment. This study established how the practice affected caregiving as a microscopic interaction based on relationships and emotions. By complying with confidentiality, the care-recipients' behaviour contradict the value of relationality which is emphasised by both the ethos of the *ubuntu* and the ethic of care because it does not embrace the values embedded in care. The tendency to conceal diagnosis led to endless search for the medical explanation of the symptoms. It did not allow a genuine triadic relationship among the caregivers, health care personnel and the patients in which the caregivers could be empowered and supported to deal with AIDS illnesses to develop. Lack of coordination between the home and hospital and poor use of medical records undermine continuity and resourcefulness of families in caregiving.

The 'doctor-patient secret' had repercussion for caregiving from the beginning. The intention to maintain a secret about HIV infection and AIDS-related illness seemed to reinforce denial and encourage stoicism which led to the need for care being acknowledged rather late. The delay in informing relatives and seeking familial care, which by all means were unusual behaviour on the part of the ill were the consequences of confidentiality which was necessarily conducive for silencing those who are infected. Studies on illness behaviour report about the delay to seek medical help which usually happens because the person experiencing signs of illness would have involved the family members in the evaluation of the symptoms and home remedies would have been tried before consulting the professionals. The experiential evidence by the caregivers provides an alternative view to the commonsense understanding that the patients who go without caregivers do so because the family members neglect them due to stigmatisation.

Part of the problem was that theoretically, the emphasis on the form of care which depended less on medicine was supposed to be compatible with the ideas embraced by the "holistic approach" to health as part of the outcry about the over-medicalised life. But it would be impossible to empower the families to deal with the chronic illness while confidentiality was maintained amidst extraordinarily distressing symptoms and the affected families were not targeted with the necessary information. This was complicated by the inefficacy of the medicines used to manage the symptoms. Surprisingly, the caregivers did not find recourse in traditional medicine when the modern doctors failed to provide plausible explanations and effective treatment for the symptoms. But, traditional medicine was mainly used in situations where AIDS was acknowledged as the reason for the limited efficacy of the medicines prescribed at the hospitals. It is from this perspective that confidentiality in the context of home-based care should be seen as constraining and counteracting possibilities of adaptations within specific local environments. This approach to care may not be compatible with the holistic approach because it works against empowering ordinary people to apply some of the practices that have worked in the past.

The finding that the caregivers would not comment about the possible link of the symptoms to AIDS is crippling to society. The fact that part of the success in the last decade in the area of public health is attributable to the health care system which recognised the role of lay people in the surveillance of disease and making of referrals on the basis of suspicious symptoms may not be ignored. This was a pillar of the primary health strategy and it was explicitly encouraged to control TB in a country that has historically been severely burdened by this disease as a result of a high proportion of labour migrants who lived in overcrowded mining compounds in South Africa. Community and family members were actively encouraged to be vigilant in public health matters.

However, with the advent of HIV and AIDS, there has been a shift from an approach that recognises the role of lay people in facilitating early detection of disease to one that adopts this trait conveniently. The emphasis by the health professionals that it may not be possible for people to speculate from the symptoms that someone is ill from HIV and AIDS unless clinical tests were made promoted the reluctance to express such suspicions within family relationships. Without sufficient motivation to pursue HIV testing in the pre-ARVs era, the widespread illness among adults could only be a matter of strong suspicion but it was difficult to obtain medical confirmation. These are some of the contradictions and controversies about HIV and AIDS. Home-based care was adopted to encourage the communities to own the problem of HIV and AIDS and facilitate the holistic care approach which emphasised nutrition to circumvent the problem of drugs unavailability. On the contrary, families were not empowered to break the silence about HIV and AIDS.

Adhering strictly to a dyadic doctor-patient relationship in the treatment of chronic illnesses while home-based care was the dominant approach to the care of the patients contradicted the policy intention to "normalise" HIV and AIDS and "bring it to the doorsteps of the communities". Basically, not sharing the HIV diagnosis with the caregivers in the interest of confidentiality was absurd because it added to the difficulties of the caregivers. The secrecy that restrained the caregivers' access to the information regarding the HIV diagnosis was not only alien to the Basotho practice of care; it also created unnecessary ambiguities in the caregiving relationships such that suspicion and resentment were common. It would be unfortunate if a not so critical medical value would be favoured at the risk of eroding familial values and trust in medicine.

A critical question, however, is in relation to the benefits of not expanding the relationship to include the family caregivers in the long-run. Given that HIV and AIDS care was provided under stringent resource allocation, confidentiality appeared to complement rationing by excluding most of the HIV and AIDS patients from health care services which they would otherwise qualify for, and perhaps overwhelm, if their status was known to the family members who eventually interceded and maintained the patient-hospital connection when the patients had lost their independence? The disparity between the caregivers who successfully negotiated treatment measures with the doctors and whose perspectives about the care needs of the patients were considered on the one hand, and those who saw themselves in consistent chaos because they could not control or influence how care should happen on the other, is an indication that being in the dark limited the extent to which medical care could be accessed. Even though professionals would not intentionally use confidentiality to harm the members of society, it ultimately contributed to poor access to medical care and support.

Most societies which may not afford medical research that would lead to HIV and AIDS vaccines and cure are waiting to share the benefits of such developments as they happen in other countries in the future. Meanwhile, HIV and AIDS care remains peripheral to medical interest in the resource-poor settings and this is implicit in the adoption of home-based care. But, medical disinterest was also likely to be discerned during clinical consultations whereby the doctors would display attitudes and practices which the caregivers interpreted as showing lack of commitment to the patients' wellbeing. Factors such as curtailed duration of consultation, superficial examinations which could also be due to the pressure to see as many patients as possible in a day, and rationing which among others was implemented through tailored treatment protocols, contributed to poor satisfaction of the service users. Since the caregivers' families did not have the financial capacity to purchase the ARVs available in one of the hospitals, the patients did not receive optimal medical care. This was because of the "explicit rationing policy" which involved gradations of access to medical care primarily on the basis of the opportunistic infections the patients had.

The caregivers experienced varying degrees of access to medical care, both out-patient and in-patient care, and this affected continuity of care for the patients. One important factor which enhanced continuity of care was when the health care personnel shared the information pertaining to diagnosis with the caregivers. Informing them at any stage of the illness trajectory reduced the stress that was commonly experienced. Knowing that the patients had HIV and AIDS-related illnesses reduced stress in the long-run because they could not only predict the actions of the health care personnel, they could also influence or persuade the hospital personnel to recommend care measures which were compatible with their own perception of the patients' needs. The caregivers who were aware of the entitlements that HIV and AIDS patients had regarding subsidised care and social care were different from those who did not know because the former received unwavering and predictable support from the hospitals.

Access to medical care influenced the perceptions of the caregivers about the health care services' responsiveness to their own needs and those of the patients. These perceptions were equally critical in influencing their caregiving experiences because care entailed responsiveness on their part to the needs of the care-recipients. The hospitals did not always respond positively to the needs of most caregivers. These tendencies were emotionally costly and consumed time and money in caregiving as the caregivers attempted to obtain credible diagnosis, medications that would work and hospitalisation. These experiences suggest that open communication between the caregivers and the patients and health care providers could affect caregiving experiences positively. They also suggest that access to effective medicines which can control the life-threatening symptoms and improve the physical appearance and capacity of the patients' bodies could be important catalysts in improving caregiving experiences.

The caregivers' experiences were also embedded in inconclusive, shifting as well as ambiguous diagnoses. Uncertainty and ambiguity about diagnosis were as unfamiliar as the 'doctor-patient secret' which prevented the caregivers from knowing the cause of the illness. Both were atypical of medical consultation encounters as people were used to situations where the health care personnel shared the information regarding diagnosis with the family members who accompanied the patients. The caregivers doubted some of the therapeutic actions of the health care workers and their intentions especially because these measures usually led to disappointing outcomes. While these outcomes did not necessarily suggest that the diagnostic procedures and techniques produced less credible outcomes, they showed that the medical practice was influenced by the prevailing social, political and economic factors.

Actually, the caregiving experiences illustrate that in their interaction with the caregivers most health care workers filtered their communication about the clinical outcomes through a medium of non-scientific factors in the larger environment of care. These responses were intrinsically linked to non-medical factors such as the concern with HIV and AIDS stigma. Usually, health surveys profile the illness that the members of society experience in both lay and medical terms but the medical perspectives usually dominate where medical care was previously sought. These ambiguities are likely to affect the quality of household social and health surveys, implying that data collecting institutions may have to take these realities into account. Uncertainty could be an inherent feature of medicine; however, it did not use to be expressed in medical consultations and was not part of commonsense knowledge. Therefore, when uncertainty surfaced amidst the controversy of confidentiality and inability of society to provide medication which prolonged the life of the people infected by HIV, it became difficult to divorce it from the concerns about unresponsiveness of some of the measures to deal with the epidemic. In these circumstances it was doubtful that the supremacy of neutrality and objectivity was upheld - expert knowledge was influenced by non-medical values too but in a very selective way because the perspectives of the caregivers were hardly considered relevant even though they would contribute considerable experiential knowledge as a result of their constant contact with the patients at home.

The tendency of doctors to prescribe for the sake of maintaining the ritual in medical consultations when there was no transparency to help the informal caregivers understand the care plan as it evolved and the circumstances around the illness situation of their relatives rendered the use of medication an emotional activity. This is also important when considering that despite the widespread view that the medicines did not work, they were perceived as essential in caregiving such that inability to have them available and included in caregiving was a source of stress. The behaviour of the patients in relation to these pharmaceutical products and their effects on the symptoms were emotionally experienced. Perhaps it is too early to hypothesise on the effects of these practices on the trust and confidence of the communities on the medical practice. Their implications for the utilisation of health facilities across the spectrum of illnesses, especially those which medicine had already domesticated, need to be followed up as medical challenges such as drug resistance intensify. However, there was impression that despite their intensive training the doctors' responses and decisions did not reflect what science promised: logic, precision, certainty and control. Certainly, the minimum package of care had implications for medical practice in the hospitals that wholly or partly depended of public financing but it would be interesting to obtain the doctors' perspective on how these stringent measures affected professionalism in the context of AIDS care. This approach may also imply that the doctors lost the opportunity to maintain the communities' trust in the hospitals because they were seen as failing to treat conditions which the hospitals were known to control effectively.

The minimum package of treatment provided inadequate medical intervention for the management of the opportunistic infections to the extent that classifying HIV and AIDS as a chronic illness in the context of this study would be problematic because the patients hardly led a symptom free life in dignity. Most caregivers could not help the patients with the ailments which persisted and symptoms which did not disappear, thus making it difficult to help them attain quality life and retain self-esteem. The ailments were responsible for the deterioration of the body which ultimately led to the confinement of the patients. While the disintegration of the body in chronic illness is inevitable, the experiences of the caregivers with the bodies of the care-recipients were essentially due to the medical treatment which did not match the ferocity of the HIV and AIDS disease and offer hospitalisation to curb severe ailments.

The consequences of the decline in health condition were extreme physical dependence and loss of control over some of the bodily processes. Under such circumstances care at home became chaotic and messy, but also demanding on the caregivers. Under these circumstances, care for AIDS patients was most likely to be relegated to the home. This shows that claiming that home-based care was the most advantageous way of caring for HIV and AIDS patients could only be viewed as rhetoric. Within the framework of demedicalisation and deinstitutionalisation physical changes such as loss of mobility and unpredictable bodily tendencies such as bowel movement rendered them unsuitable for occupying the orderly, routine-based and sanitised hospital settings and for using other public spaces such as transport facilities. The caregivers felt shame and would not bring the patients who could not walk due to severe pain and weight loss, or had bouts of diarrhoea into public. The concern with managing bodily matter which transgressed boundaries and defied the rules of body containment placed self-imposed restrictions on the use of public spaces. This was because apart from being some of the metaphors of AIDS, these conditions defied cultural symbols of 'healthiness' and purity, therefore they degraded the dignity of the patients which the caregivers safeguarded by waiting for the symptoms to subside, especially when they were confident that the patients would not be admitted. Consequently, immobility and 'antisocial' symptoms meant that it was extremely difficult to seek and access medical treatment under such physical conditions. These were also compounded by poverty and inability to arrange suitable transport.

From this point of view, demedicalisation of AIDS care as represented by medical drugs which did not include ARVs and restricted in-patient care indirectly reduced the demand for medical treatment even though the need for medicines persisted because the symptoms did not disappear. The connection of the patients with the hospitals was curtailed. The reality of the caregivers who provided care without using medication yet the patients were in extreme pain or had uncontrollable symptoms highlighted that the home and hospital spheres were weakly integrated. This situation deteriorated further with the progression of the illness and the onset of confinement which basically constricted care options and perhaps hastened death. This cautions us about one of the commonsense presumptions that families hide AIDS patients. Also, what could appear as reduced dependence on medical care and decline in bed occupancy in hospitals due to deinstitutionalisation of care was actually deprivation and exclusion of this category of the population from health care. In this way, deinstitutionalisation and demedicalisation were both consistent with rationing. They furthered the interest of the familiar practice of costs cutting on social expenditure which was introduced through the neo-liberal policies.

The caregivers had poignant experiences when the hospitals would not render the forms of medical care which attended to the needs which arose in the home sphere and the doctors ignored their perspectives. By denying the patients hospitalisation despite their life threatening symptoms, the hospital services failed to be responsive to the patients' needs and the health care personnel disregarded the concerns of the caregivers in these situations, especially their anxiety. Failure to hospitalise the patients who were expected to be admitted because they had life-threatening and distressing symptoms and returning home with patients who could not walk or eat was discouraging. Perhaps, these experiences could be alleviated if the health workers' decisions as they implemented the policy on the deinstitutionalisation of AIDS care were made in a transparent manner for all the caregivers. That is, in the same way the caregivers who identified their relatives as AIDS patients understood how home-based care affected them because there were fewer ambiguities. Possibly, there would also be less anxiety because the caregivers' ability to predict the actions of the hospital personnel would improve. Most importantly these practices bolstered the perception that the doctors were not committed to providing effective treatment and the suspicion that AIDS diagnosis was possibly responsible for such prejudice. Definitely, the caregivers benefited when the patients were occasionally hospitalised, unfortunately, such respite was not available to the caregivers of the patients with inexplicable illnesses yet they were likely to be the most distressed as a result of operating with ambiguities.

The stress which the caregivers undergo as a result of their role and the somatic problems they experience need to be systematically documented if the ideal of 'caring for the carer' is to be achieved. Probably a society could only provide humane care for HIV and AIDS patients at home if such a decision is not simultaneously influenced by demedicalisation and radical rationing of resources because it would mean that the patients would continue to receive the necessary medical attention while at home; and where the care relationship is humanised and not dominated by confidentiality which excludes the caregivers yet hospital admissions and stays were restricted. These should be regarded as some of the prerequisites of continuity of care. They would lead to the hospital teams sharing the care plans with the informal carers at home and a two-way communication between the home and the hospital would enhance caregiving and produce positive experiences. For a disease that is psychologically burdening, resorting to confidentiality may appear hassle-free for resource constrained hospitals but it has far reaching consequences for family relationships.

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