

Confidentiality or continuity? Family caregivers' experiences with care for HIV/AIDS patients in home-based care in Lesotho

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Abstract

In the context of poor access to antiretroviral therapies in sub-Saharan Africa, the minimum treatment package intended to treat opportunistic infections common with HIV infection is inadequate but appealing, since it presumes universal coverage of medical care for patients living with HIV and AIDS. The overall objective of this study was to analyse the challenges which family caregivers encountered in home-based care when they tried to access medical treatment for home-based AIDS patients in the context of confidentiality and limited medical care. A qualitative study using in-depth interviews with a sample of 21 family caregivers – 16 females and 5 males aged between 23 and 85 years was conducted with the assistance of health personnel in two hospitals in Lesotho. Using the concept of continuity of care, this article discusses the experiences of family caregivers about home care, including their experiences of adherence to confidentiality by health care professionals and non-disclosure of AIDS as the context of illness, the circumstances under which the caregivers initiated caregiving and sought medical care, and how these factors could be stressors in caregiving. There was continuity of care where the caregivers obtained hospital support. However, when confidentiality was adhered to the caregivers were frustrated by lack of information, disrupted treatment, exclusion of their perspectives in medical care, failure to secure hospitalisation, ambiguous goals and non-responsiveness, so that continuity of care was jeopardised. Thus it can be concluded that professional-assisted disclosure benefited the patients because it facilitated continuity of care through the caregivers.

Keywords: Lesotho, HIV/AIDS, confidentiality, caregiving, continuity of care, ethic of care.

Résumé

Dans un contexte africain sous-Saharien où l'accès aux thérapies antirétrovirales est très limité, le paquet minimum de traitement destiné au traitement des infections opportunistes liées à la séropositivité est inadéquat mais attirant puisqu'il suppose une couverture universelle de soins médicaux pour des malades vivant avec le VIH/SIDA. L'objectif global de cette communication est d'analyser les défis auxquels les soignants familiaux font face en soins à domicile lorsqu'ils essaient d'avoir accès au traitement médical pour les malades du SIDA dans un contexte de confidentialité et des soins médicaux limités. Une étude qualitative employant des entretiens détaillés auprès d'un échantillon de 21 soignants familiaux (16 femmes et 5 hommes âgés de 23 à 85 ans) a été menée grâce à l'aide du personnel de santé dans deux hôpitaux au Lesotho. En utilisant le concept de continuité de soins, cette communication met en relief des expériences des soignants sur les soins à domicile. Cette communication examine des expériences des soignants familiaux sur les éléments suivants : l'adhésion par les professionnels de santé et de soins à la confidentialité et à la non-divulgence de séropositivité comme étant le contexte de maladie, les circonstances sous lesquelles les soignants ont initié les soins, les soins médicaux suscités, surtout le diagnostic et le traitement, ainsi que l'hospitalisation et la manière dans laquelle ces facteurs pourraient être à l'origine du stress chez les soignants. On a constaté que la continuité des soins dans le cas où les soignants recevaient du soutien hospitalier – l'information, un traitement gratuit des multiples symptômes et l'hospitalisation de manière prévue et consistante. Cependant, lorsqu'il y avait adhésion à la confidentialité, les soignants étaient frustrés par le manque d'information, un traitement perturbé, l'exclusion de leurs opinions vis-à-vis les soins médicaux, ne pas pouvoir assurer l'hospitalisation des malades et les objectifs ambigus, la non-réceptivité et la continuité a été compromise. En conclusion, on constate que en divulguant sa séropositivité avec l'aide professionnelle a énormément aidé les malades car cela a facilité la continuité de soins assurés par les soignants.

Mots clés : Lesotho, VIH/SIDA, confidentialité, soigner, continuité de soins, l'éthique de soins.

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Introduction

Lesotho has one of the highest HIV infection rates in the world, estimated at 31% among adults aged 15 to 49 years in 2003 (Ministry of Health, 2003), and ranging between 21.9% and 24.7% in 2005 (UNAIDS, 2006). As with most resource-poor countries in sub-Saharan Africa, medical treatment provided for patients with AIDS-related illnesses in the public health sector before 2004 did not include antiretroviral drugs (ARVs) and the approach before this date was “a *minimum package of care*” intended to treat some of the common opportunistic infections and reduce hospitalisation (Government of Lesotho, 2002). For example, treatment for oesophageal candidiasis and cryptococcal meningitis as well as sexually transmitted infections (STIs) and tuberculosis (TB) was free (Ministry of Health and Social Welfare (MoHSW), 2000). However, due to inadequate and poor access to medical treatment, chronic illness persisted and AIDS-related deaths increased, though the AIDS-related root causes of these deaths were usually not disclosed.

Home-based care was adopted to avert the ever increasing need for hospitalisation, and continuity of care for patients and support for affected families were identified as the pillars of this strategy (Government of Lesotho, 2002; MoHSW & World Health Organisation, 2002). Amidst the high incidence of adult morbidity and death, the policy of confidentiality regarding HIV diagnosis prevailed, leading to a situation whereby ‘chronic illnesses’ became a generic label used in public health documents to gloss over symptomatic AIDS illnesses, especially in the context of home-based care.

The objective of this article is to analyse the caregiving experiences of a sample of 21 family caregivers of patients with HIV/AIDS-related illnesses who were cared for at home and obtained medical treatment at two hospitals in Lesotho. It examines their experiences in obtaining medical care for the patients under the then prevailing confidentiality practices and the limited medical treatment available.

HIV and home-based care

The encouragement of home-based care in the era of HIV/AIDS was intended to reduce the economic and human resource pressure, which health care systems especially hospitals faced. As a result of increased chronic illness due to HIV/AIDS in the hardest-hit and poorly resourced countries, “people who are not normally users of health care: young adults” (Barnett & Whiteside, 2002, p.308) sought hospital admission. Curtailing hospitalisation through informal home care in order to avert frequent and long hospital stays is explicit in AIDS care (Mupedziswa, 1998; Van Dyk, 2001). Although doctors

maintain high autonomy in their day-to-day decision-making, their decisions reflect and are influenced by political, economic, social and cultural factors (Johnson 1993; Powell-Cope & Brown, 1992; Schoepf, 1991).

The treatment and management of HIV-related chronic illnesses usually commence with ambulatory patients seeking health care services independently. However, as their health conditions deteriorate, mobility and independent functioning decline. Without comprehensive treatment, which includes the highly active antiretroviral therapies (HAART), acute illnesses are common in poor high HIV prevalence countries. The transition from being HIV seropositive to having AIDS symptoms may be dynamic, and patients with a tenuous link to the health care system may face a crisis when they fall ill. The universally accepted value is that even home-based care patients should have access to medical care when they need it. Access to health care entails timely use of health services to attain the best possible results (Andrulis, 1998). In a study including out- and in-patient care recipients, Cunningham, Hays, Ettl, Dixon, Liu, Beck and Shapiro (1998) found that patients with symptomatic HIV illnesses generally had poorer access to medical care than patients with other chronic diseases, due usually to the high cost of drugs and reduced incomes as a result of illness.

Confidentiality, stigma and discrimination

Maintaining confidentiality in HIV/AIDS when most of the care is provided by family members is controversial. Confidentiality has mainly been considered from the perspective of protecting people infected and affected by HIV/AIDS from stigmatisation (Corey, Corey & Callanan, 2003; Gwyn, 2002). Negative attitudes such as unwillingness to associate with persons with HIV/AIDS are experienced from “sacred domains – family, medicine, and church” (Poindexter, 2005, p.2). Contrary to the good reasons for maintaining confidentiality, research conducted in Western cultures suggests that informal caregivers for patients living with HIV/AIDS may resent confidentiality if it marginalises them and deprives them of pertinent information about the illness while they assume the bulk of the responsibility for the patient’s wellbeing (Colledge & Maddison, 1992), and are expected to observe universal precautions to prevent HIV infection. Similarly, it is recognised that shared confidentiality has the potential to de-stigmatise HIV/AIDS in resource-poor contexts where families and communities shoulder most of the care responsibility in home-based care (Campbell, n.d.). Ironically, disregarding this principle may have far-reaching consequences for the agencies responsible for the different components of ‘governmentality’ such as surveillance and the compilation of statistics (Johnson,

1993) on the epidemic. Trust in the health care services may be jeopardised (Vedder, 1999) because the integrity of health care professions also depends on maintaining confidentiality, especially where it is promised (Jackson, 2002; Van Dyk, 2004).

It is also critical to acknowledge that certain chronic illnesses, especially those which incapacitate the patients, cannot be managed in an exclusive doctor-patient relationship (Haug, 1994) without involving family caregivers. The involvement of family members in assisting relatives with chronic illness includes helping them to access medical treatment (Thomas, Morris & Harman, 2002). It is in this context that the importance of expanding the healing relationship to include family caregivers of elderly patients with dementia (Haug, 1994), and providing both patients and caregivers who manage chronic illnesses with comprehensive information about aspects of the treatment strategies (Rajaram, 1997) are recognised and necessary strategies. Labrecque, Blanchard, Ruckdeschel and Blanchard (1991) found that caregivers of cancer patients considered provision of information a form of social support which alleviated their uncertainty, and that when illness was serious, interaction between the patient, the doctor and the family member was crucial. Poor communication between caregivers and physicians can lead to the former expressing displeasure with physician support (Glaser, Rubin & Dickover, 1990, cited in Haug, 1994). When medical encounters between patients and their doctors are guided by confidentiality, family caregivers are likely not to obtain essential information about the illness if there are barriers to practicing “shared confidentiality”.

In most African societies, maintaining confidentiality which excludes family members in the context of care is a peculiar practice which contradicts the fundamental values which provide the basis for social cohesion. Some writers have described HIV-related confidentiality in the African cultural context as controversial (Fombad, 2001; Jackson, 2002). Firstly, home-based care is typically based on familial obligations embedded in the *ubuntu* philosophy (Okolo, 2002; Ramose, 2002). “*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” (Ramosé, 2002, p.643). It espouses the notion of caring which is inherent in most human relationships and is consistent with the ideas of the theorists of care (Bowden, 1997; Kuhse, 1997); Noddings, 1984; Sevenhuijsen, 2003; Tronto, 1993) who adopt the *ethic of care* and insist on avoiding the trap of viewing care as inherently burdensome as it is commonly understood. Instead, they emphasise values such as human relationships based on interdependence, trust, openness, acknowledging emotions and dependence, and responsibility to particular others in this social

practice. Both the *ethic of care* and *ubuntu* are contrary to what Noddings (1984) describes as the Western approach, based mainly on *justice* principles of reason, abstraction, universalism, rules and rights; and emphasise local contexts and situation specific circumstances when dealing with problems.

Secondly, family members are usually part of the responses to illness (Liddell, Barrett & Bydawell, 2005) and are present in medical encounters between patients and physicians (Andersen, 2004). Furthermore, despite confidentiality, physicians in Africa mostly share information on diagnosis with family members for serious diseases such as cancer, and may rely on the family in disclosing or withholding diagnosis from patients (Harris, Shao & Sugarman, 2003; Holland, Geary, Marchini & Tross, cited in Gotay, 1996). These practices may be seen as ways in which biomedicine has been adapted to the cultural values of communality and sharing or the ‘Africanisation of biomedicine’ (borrowing from Finkler, 2004 – ‘Mexicanisation of biomedicine’). When HIV/AIDS is involved, the issue of confidentiality becomes particularly problematical, especially in societies where family relationships play a significant role in ensuring that the patients obtain humane care at home (Chimwaza & Watkins, 2004). It is thus important to examine how confidentiality affects continuity of care, as “an essential attribute of a well-functioning health delivery system” (Donaldson, 2001, p.255).

The definitions of continuity in the context of chronic illness emphasise coherence, comprehensiveness and responsiveness of care services, provided on a long-term basis and across different spheres of care, the result of which is improved health outcomes for individual patients (Benjamin, 1989; Haggerty *et al.*, 2003; Mainous & Gill, 1998; Woodward, Abelson, Tedford, & Hutchison, 2004). Haggerty *et al.* (2003, p.1220) identify two key aspects of continuity as “care of an individual patient and care delivered over time”. They further identify the three types of continuity as informational, management and relational continuity, all of which are crucial in chronic illness. It is the informational aspect which makes Donaldson’s (2001) conceptualisation relevant to this discussion. Donaldson (2001, p.262) adopts the agency theory to understand continuity and defines it as “the degree to which health care activities are structured to increase information available to a clinician and to increase the likelihood of goal alignment between the patient and clinician”. Donaldson’s agency model is useful because it emphasises the relevance of information sharing between actors who inherently have asymmetrical access to it – doctor and patient. Although the model identifies the relevance of continuity in chronic illness, it does not accommodate the inevitable loss of agency by the patients as their health dwindles,

and the need for information sharing and goal alignment with the caregivers to ensure uninterrupted care overtime.

Research is relatively silent about how the dynamics underlying the HIV/AIDS illness and the care environment, as well as the inevitable loss of independent functioning by patients and confidentiality may be experienced by family caregivers when they try to meet the care needs of home-based patients over time. The question of access to treatments, which exclude ARVs, to alleviate AIDS-related opportunistic diseases is important even today because the adopted approach – ‘scaling-up’ or ‘rolling-out’ of ARVs – does not guarantee immediate access of all the people who need them. However, the focus on ARVs, while unavoidable, might have inadvertently overshadowed the question of access to health care services as currently made available to the majority of PLWHA.

Methodology

Study design

This article presents and analyses some of the findings that emerged from a qualitative study conducted in Lesotho from February to August 2004. The study focused on the caregiving experiences of family members who became involved in home-based care after 2002, when this approach to care for patients with AIDS illnesses was formally adopted and appeared in policy documents in Lesotho (Government of Lesotho, 2002; MOHSW & WHO, 2002). The study participants were identified with the help of the hospital personnel responsible for HIV and AIDS counselling and testing in two hospitals. The hospitals maintained registers of the patients who were in home-based care within their respective health service areas (HSAs) and they provided information on the patients and where they stayed. The counsellors used the information to identify potential interviewees for the study and accompanied the researcher who was responsible for conducting the interviews to make first contact with the caregivers.

Purposive sampling was used to select the caregivers using the following criteria: (a) a current or ex-caregiver who provided care for a family member diagnosed HIV/AIDS positive at any one of the two hospitals, (b) care was provided at home, (c) caregiving was provided after 2002, (d) current caregivers who had experience of what was involved in home-based care, and (e) willingness to be interviewed at length using a tape-recorder. The study adopted a strategy similar to Taraborrelli's (1993) study on Alzheimer's carers, in which she discovered the value of interviewing current and ex-carers and realised that each provided different perspectives.

Setting

The study area comprised communities which received health care services from two hospitals both located in the Berea district in Lesotho – the Maluti Seventh-Day Adventist hospital – a church-owned institution – and a government-run district hospital. Maluti Hospital prescribed ARVs on the basis of the patients' ability to pay for laboratory tests, monitoring and ARVs (Government of Lesotho, 2002b) at the time when government health care policy did not provide for ARVs in public institutions.

Sample

Twenty-one caregivers of patients who had been diagnosed with HIV/AIDS and received medical care which did not include ARVs from the two hospitals were studied. Twelve participants were identified within the Maluti health service area (HSA) and nine from the Berea government HSA by the counsellors, based on the criteria specified above. The caregivers resided in the peri-urban areas of the district administrative town and the rural villages of the district. There were five male and 16 female caregivers aged between 23 and 85 years. The ex-caregivers exited the role because the patients had died and there were instances where the patients died during the fieldwork. The caregiver relationship to the care-recipient included mother, father, grandmother, brother, sister, aunt, uncle, mother-in-law, son and daughter. Only three caregivers were informed by health care professionals about the HIV-positive status of the patients; most suspected the patients had AIDS-related illnesses. Most of the caregivers cared for one family member, but there were some who provided serial or simultaneous care to more than one patient at home. Five caregivers provided care for more than one patient in sequence, while four of the participants provided care for more than one family member simultaneously. They included a father who cared for his two teenage children and spouse; a mother for two daughters; and a grandmother who cared for two grandsons.

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; it did not necessarily imply the duration of illness as the two tended to vary; in many cases caregiving was ‘delayed’. Also, the caregivers' perspectives of the duration, as expressed in terms of the period spent in caregiving, differed from their subjective verbalisation of the time spent providing care. Most caregivers tended to preface 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.

Ethical considerations

The research questions and methods of data collection were shared with the administrative officials at the Lesotho AIDS Programme Coordinating Authority (LAPCA) – the statutory body responsible for authorising research on HIV/AIDS in Lesotho; and the health authorities at the two hospitals. The health workers provided input to the approach of the study, by advising that the research should not lead to unintended disclosure of the HIV status of the patients, as they believed the patients had not informed their caregivers. They were informed that the research was for academic purposes, the findings would be published without revealing the caregivers' identity, and they were free to refuse to participate or withdraw their participation at any point. The study was broadly introduced as intended to obtain their experiences about providing care for relatives at home without specifying the HIV status to the patients.

Data collection

The phenomenological method was used to obtain the perspectives of the caregivers about their experiences. 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 ... of the experience (Moustakas, 1994, p.13).

The *epoché*, a requirement in phenomenological research, that researchers suspend or bracket their assumptions concerning the phenomenon being investigated was adopted (Cresswell, 1998; Moustakas, 1994). This allowed for an interviewing approach which did not impose assumptions and existing knowledge about home-based care, such as the close link with AIDS-related illness. All the respondents were interviewed in person in Sesotho by the first author.

The interviews were guided by the interviewer but were allowed to proceed in a conversational and informal manner. Interviews took place at the home where care took place in cases where caregiving was on-going, or at the caregivers' own home if they had exited caregiving. The decision regarding the venue of interviews was left entirely to the caregivers, and in cases where caregiving was on-going they opted to be interviewed in the presence of the patients; sometimes because they hoped to

initiate or continue their dialogue with the patients about the illness or did not intend to cause them anxiety about the subject of the interviews. The interviews generated evidence in the form of first-person descriptions of life experiences in caregiving.

Data analysis

The procedure followed to analyse the caregivers' experiences followed the phenomenological method adopted by Worthen and McNeill (2002) and Riemen (1998) in their studies on how individuals experienced supervision and caring interactions, respectively. The ultimate outcome of a phenomenological study according to Polkinghorne (quoted in Cresswell, 1998, p.177) is to: "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'"

The following analysis and discussion of the caregivers' experiences is intended to provide a description of what the interviewees went through in caregiving, and how social, medical and policy factors shaped their experiences.

Results

This section presents the caregivers' experiences with some of the issues which they perceived as necessary elements of effective home-based care: availability of a suitable carer, knowing the patients' diagnosis, availability of medication at home, and access to the hospitals for outpatient and inpatient care. Although the patients initially sought medical care from the hospitals on an ambulatory basis independently, their noticeable transition to poor health rendered the involvement of the family members necessary. The experiences of the caregivers with the physical changes which marked the illness of their relatives are discussed below.

Delayed care

Some caregivers knew only at a late stage about their relatives' illness; they narrated stories about their 'delayed care'. They 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:

When she phoned my neighbour's house she told me she still couldn't go to work ... 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, until we terminated the call ... She said she could still make porridge for herself but I felt she was not telling the truth ... I was so worried (Caregiver 12).

When I got the message, I could sense the seriousness of her illness even before I saw her... her in-laws didn't inform or request me to help her... there was no adult caring for her. I found that she was being helped by her son, that boy who you saw! ... I was touched when I found her because I could see that she was very ill ... She was already lying down ... I was shocked because I didn't expect that when you are told for the first time (Caregiver 8).

The caregivers' efforts when they assumed the caregiving responsibility included accompanying the patients to the hospital to obtain medical treatment, and negotiating what they perceived as appropriate treatment for the patients on the basis of their experiences at home.

Diagnosis: the need to know and 'patient-doctor secret'

Part of the caregivers' action was helping the patients to obtain a diagnosis for the life-threatening illnesses which they experienced. The common view was that when illness involved HIV/AIDS-related diseases the doctors and patients managed this with secrecy, making it difficult to obtain information about the HIV diagnosis. However, they believed that at a certain point, it was possible to link the symptoms to HIV/AIDS, though medical confirmation was always necessary. This knowledge was experiential and obtained from public health information in the mass media:

We hear it is a personal secret with the doctor, what we only see are the symptoms because we have been educated about AIDS symptoms ... people don't agree that they have it or even mention ... There is secrecy around HIV/AIDS and when people have it they will mention all the problems they have to the extent of saying it is a finger or a thigh or just body aches but they never mention that they have this infection (Caregiver 1).

The caregivers perceived diagnosis as integral to obtaining and being prescribed relevant treatment. They could obtain free and effective treatment if TB was diagnosed. As a result, in some situations the search for a diagnosis did not dissipate. Their experiences when they tried to obtain medical diagnoses were one of the major themes in their narratives:

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 ... 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 (Caregiver 2).

Some caregivers would not have a conclusive diagnosis until the patients died, others established clinical diagnosis late when the disease was advanced:

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 (Caregiver 8).

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 (Caregiver 9).

Efforts to obtain a credible diagnosis were part of the caregivers' perceived role, in order to help the patients obtain relevant medical care while at home. Some caregivers actually persuaded the doctors to review the earlier medical diagnosis when they continued to experience complex symptoms. HIV tests were also requested, especially when the symptoms caused suspicion or did not respond to prescribed medication, including therapies which were known to work, such as the six-month rifampicin based TB treatment. Three caregivers who requested to have the initial diagnosis reviewed, obtained information about the HIV status of the patients. They reported that following the review the patients' quality of care and outcomes improved. Their experience suggests that obtaining information on the HIV/AIDS status of the person being cared for freed caretakers from the search for a diagnosis, and allowed them to attend to the illness with assistance from the health care providers. The experiences of those who progressed from not knowing to being informed convincingly demonstrated the advantages of the latter situation:

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; I could not understand what was happening. 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 ... Since he started taking the medication which he started in 2002 ... he has stabilised 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 (Caregiver 5).

Disruption of medical treatment

Despite their belief that medication was integral to effective home-based care, some caregivers reported disruptions in the use of medication. This was because some doctors did not respond in a helpful and compassionate manner. A caregiver described her desperate attempts to ensure that the treatment was not disrupted:

I was used to a situation whereby we would go to collect her monthly prescription even before her tablets finished. But 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 ... I didn't know what I was doing, I was anxious that she would spend days without medication but I did not know what would happen after these three days. I didn't know where I would go ... 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, said two tablets a day (Caregiver 2).

Similarly, when the patients had bouts of diarrhoea, the caregivers perceived it as embarrassing to use public transport. They preferred private transport, but this was unaffordable to most affected families. Some caregivers 'delayed' consulting hospitals with the hope that the symptoms would improve or helplessly watched "the disease finish" their loved ones, because their perception was that the hospitals would reject them anyway:

When we went so that she could be admitted and have a drip, they refused saying she would have to treat the diarrhoea at home first. What kind of hospital is that? ... The nurse wrote a referral letter to the hospital saying that it seemed she did not have blood and water in her body system ... he [doctor] read her health record book and it was clear that she had to be hospitalised, so when he suggested otherwise, what could we do? I was thinking that may be they did not want to admit her because she had diarrhoea. Patients who have diarrhoea are associated with this latest illness – HIV/AIDS; probably the doctor did not like that (Caregiver 12).

In some situations, caregiving continued for extended periods without the use of medication, despite the patients experiencing severe symptoms:

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 (Caregiver 8).

The need for hospitalisation

Severe illness intensified the role of the caregivers and the need for occasional hospitalisation. Some conditions caused anxiety because they disrupted care and interfered with food and medication intake, which they considered as necessary to life:

I wanted her 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 (Caregiver 9).

I was saying she should go to the hospital because her skin has become very dry ... I was hoping that if she went to hospital she would get a drip (Caregiver 6).

The caregivers considered hospitalisation when the patients experienced severe pain and life-threatening symptoms such as chest pains, difficult breathing, coughing, diarrhoea, nausea, STIs and vomiting. Under such circumstances, they consulted the hospitals with the expectation that the patients would be admitted. For the caregivers, hospitalisation was associated with positive experiences, because doctors treated problems which would not be treated if the patient remained at home:

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 feeling better, I felt encouraged (Caregiver 15).

Hospital X brought her life back given the way she was when she was first admitted. I had lost hope... She usually spends about 15 days there and comes back. She is usually better and can do a few chores (Caregiver 17).

Access to in-hospital care

The caregivers were generally aware that it was difficult to secure inpatient care, with non-admission and short stays common. But a few caregivers reported frequent readmission of the patients due to recurring illnesses:

The doctor had said whenever she complained about pain I must just bring her to the hospital ... We kept doing this, until she said: mother now I am tired, it has been a long time since you started taking me up and down, just leave me as I am (Caregiver 9).

But many caregivers reported several attempts to obtain hospitalisation without success. Some were discouraged by the common perception that the hospitals were reluctant to admit patients who were highly dependent on nursing care or had diarrhoea. When the patients were not admitted, the caregivers felt rejected and this was experienced painfully, making them doubt the intentions of such doctors:

She was very weak ... 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. I was angry ... It was painful, but I said that doctors know ... 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 (Caregiver 12).

Some caregivers convinced reluctant care-recipients that hospitalisation was necessary and when they were turned down they felt powerless, and this situation created difficulties in care relationships:

I convinced her that if she could be admitted and get blood [transfusion] she would be better, it was my song everyday. 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 hospitalisation I got discouraged, I wished I could say something, thereafter ... she spent most time sleeping (Caregiver 6).

Knowing patients' HIV status improved access to medical care

Despite the general difficulties, in instances where caregivers identified the care-recipients as 'HIV/AIDS patients' they reported relatively easy access to medical care, which included free treatment of all the symptoms experienced and hospitalisation. However, TB patients with other complications unlinked to the TB diagnosis did not receive free treatment for the myriad symptoms they gradually experienced. This also happened if they developed other illnesses following discharge from the six-month treatment. Separate fees were charged for therapies meant to treat these 'extra' symptoms:

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 hospitalised or attends her check-ups we don't pay anything. She only paid when she had diarrhoea and was hospitalised for one week ... she does not pay for TB treatment and staying in hospital. But if she has other complaints and pains she pays for the medicines (Caregiver 17).

Where the HIV/AIDS status of the patient was shared with the caregivers, the health workers discussed the support available from the hospitals, and encouraged the caregivers to use the services. Knowing that the patients would obtain free treatment because they were diagnosed with HIV or TB was also an advantage, since the caregivers did not consider fees in their decision-making and it contributed to continued contact with the hospitals. The difference in the experiences of the caregivers below illustrates this point:

She became very sick again. I had lost hope completely. Since she does not pay any fees at the hospital, I just make sure that I get 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 (Caregiver 7).

I had really wanted to take him to hospital at some stage when he started to show things which I had never seen – the diarrhoea worried me because although I tried to give him a hydrant solution I saw that he was losing lots of water. But I could not because I did not have money. The hospital was not telling people that when someone has this infection, the patient could be treated for free. We thought that he would need money to be admitted (Caregiver 16).

Informed caregivers were able to admit their patients whenever their conditions warranted it at no personal cost. They considered it helpful because apart from respite, the symptoms improved subsequently:

He's not on antiretroviral drugs. 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 headache ... every time we notice something that bothers us we don't waste time, we take him to the hospital (Caregiver 5).

Discussion and conclusions

Effective home-based care depends on uninhibited communication about the patients' illness between the various actors involved in the provision of care in the two domains of care – home and hospital. It begins with the illness being brought to the attention of the medical doctors on time, and the doctors' diagnosis, prognosis, and prescription of realistic treatment options and, importantly, communicating these to the patients and their family members. Family members who are responsible for rendering care at home expect the health care system to augment their efforts and provide relevant treatment for the conditions which are brought to medical attention. Doctors assist the family members if they make them aware of the constraints which a particular diagnosis presents to medicine, the health care system and the support available under different circumstances. However, in the context of HIV/AIDS illness this normative approach to care is undermined by both medical and non-medical factors which form part of the care environment in the affected communities. One of the key elements of the HIV/AIDS care environment is confidentiality. As this article shows, how the health care providers manage this factor determines the experiences of the family caregivers when the patients with symptomatic HIV/AIDS are in home-based care.

The policy provision of a minimum package of care for PLWHA, even though it does not include ARVs, is appealing because it is presumed that there is universal coverage for all patients with symptomatic HIV. However, the studied caregivers did not have uniform access to medical care for the changing needs of patients. They had different experiences with access to medical care, despite reporting virtually similar illness patterns which prompted seeking medical care.

Mostly, the caregivers' experiences varied depending on whether or not the health personnel informed them that HIV/AIDS was the likely cause of their relatives' illness. Knowing that the patients were ill because of HIV infection was advantageous, and the caregivers who knew tended to express satisfaction with the informational and medical support they obtained from the hospitals' personnel. They found hospital support predictable and responsive to the emergent needs at home. On the other hand, the caregivers who did not know 'what they were dealing with' had chaotic caregiving experiences. For instance, when TB was part of the diagnosis the patients obtained free TB treatment, but problems arose when TB patients experienced 'extra' symptoms or relapse, because the caregivers had to consider hospital fees and were charged for the treatment received. This means that the caregivers whose patients had other opportunistic infections besides TB faced severe financial constraints because they were not aware that the patients qualified for free health care services in the hospitals. Doctors would know that with HIV, the infections could recur; including TB which has been found to relapse following completion of treatment (Carter, 2007). However, health professionals' concern not to contravene confidentiality once the caregivers are part of the patient-providers relationship is a challenge which can jeopardise the provision of treatment if not managed well. The practices followed should benefit the patients and their caregivers equally, by facilitating continued use of health care services and reducing preventable stress among the caregivers. Illness and the related incapacity show that human existence is inherently based on dependency and vulnerability which necessitate care by others (Bowden, 1997 ; Sevenhuijsen, 2003; Tronto, 1993).

The two points at which disruption in the patients' provision of care are likely to occur suggest that it is not feasible to provide care within a confidential doctor-patient relationship for PLWHA and not involve family members. Firstly, disruption may occur when the patients become severely ill following periods of independent functioning which included seeking medical treatment on their own. Carricaburu and Pierret (1995, p.66) refer to being HIV-positive as "a situation at the risk of illness" but not being chronically ill yet, because people living with HIV may be asymptomatic.

When some of the caregivers initiated caregiving, the patients were on medication but did not have suitable caregiving at home. This suggests that explanations to the effect that one of the main obstacles to home care may be the absence of willing and able caregivers (Williams, 2002) may be inadequate. Diagnosis with a chronic disease provides the opportunity to make such arrangements, and this is one area in which some of the healthcare providers were able to be facilitating when they involved family members. Akintola (2006) indicates that home-based care would benefit from hospitals making proper assessments of the homes before HIV/AIDS patients are discharged. Doctors would know that incapacitation was inevitable and that the patients would eventually depend on caregiving, while long-term hospitalisation would be difficult to secure.

Secondly, care was disrupted when the patients experienced acute illness or their condition deteriorated despite being on treatment or following completion of treatment. The changes entailed severe illness episodes which could be alleviated by occasionally admitting the patients. Again, the caregivers who knew that the patients were ill because of HIV infection reported that the patients obtained the needed medical care, as indicated by availability of medication at home and hospitalisation. These caregivers did not experience disruptions in the patients' medical care following the HIV/AIDS diagnosis, while some noticed that the symptoms occasionally improved. As some understood the situation, the government was responsible for providing free treatment for HIV/AIDS patients. They also had the perception that the patients were admitted whenever they experienced severe symptoms, thus rendering this service predictable. They could claim the patients' entitlement to "social care" (Daly & Lewis, 2000) , and this seemed to influence how the hospital personnel addressed their needs over time.

Most caregivers who attempted to obtain admission for patients had poignant experiences. This happened for example in cases where caregivers returned with a patient from a hospital visit and, because the obviously sick patient had not been admitted, the community judged the patient to be suffering from AIDS, and stigmatised the carer and the patient. Carers reported frustration, anger, helplessness and disillusionment when the health care providers did not take their perspectives into account. Sometimes the patients were not admitted because of some of the symptoms which caused the caregivers' anxiety. As Benjamin (1989) argues, access to health care may be improved by recognising that, although HIV/AIDS is a chronic illness, patients occasionally need acute medical care which requires hospitalisation. While most of them were never admitted, it was important that the caregivers who initially encountered similar problems realised that they established rapport with the health

professionals following communication of the HIV status of the patients and review of diagnosis, which in turn led to improved access to medical care including hospitalisation. In some instances, the caregivers did not have medical supplies or were prescribed obscure treatments which did not seem to take the caregivers' perspectives into account. These experiences suggest that there was a risk that care services would be fragmented once the patients in home care were too ill. The findings also highlighted that there was another side to the relationship between frequency of admission to hospital and continuity. Contrary to Mainous and Gill's (1998) observation that chances of future hospitalisation tended to be low where there was continuity of care with a doctor, the study suggested that non-attendance at hospital could also be the result of deprivation and poor service delivery which disrupted continuity.

Haggerty *et al.* (2003) conceptualise continuity of care as the delivery of services in a consistent and prompt manner, designed to meet individual needs over time. Integral to this approach is flexibility in the management of long-term care which is continuously adjusted and responsiveness to the needs of the patients and their families. These experiences support the findings that continuity existed when care for home-based patients did not involve extraordinary attempts by the caregivers and was responsive (Woodward *et al.*, 2004). We need to consider that it is as crucial to have information flow between spheres of care, and communication among the actors involved in the management of chronic illness (Haug, 1994; Rajaram, 1997), as it is for continuity of care (Donaldson, 2001; Haggerty *et al.*, 2003).

Similarly, Donaldson's (2001) definition of continuity emphasises the role of information from a doctor in improving "goal alignment" between themselves and the patients. Donaldson's agency model of continuity identifies acquisition of information about the patients' needs and its correct use by clinicians in therapy as necessary for providing care that is responsive. This may imply that in situations where caregivers are patients' 'intercessors', the information should be shared with them. Therefore, it is plausible that the caregivers who were informed about the HIV/AIDS status of the patients experienced satisfaction with the services, because the actions taken in the hospitals were in synchrony with their needs and they understood the prognosis. The caregivers who were of the view that their perspectives concerning the patients' needs were disregarded, viewed the health professionals' actions negatively, thus suggesting lack of goal alignment in their care situations.

In conclusion, the evidence from the study suggests that continuity of care for AIDS patients who depend mostly on home-based care and family caregivers for their well-being

could be a challenge for caregivers in contexts where health care practitioners rigidly adhered to confidentiality, instead of providing counselling and encouraging shared confidentiality. The ways in which medical practice responded to the disease mainly reflect adaptation which was biased towards western medical values, while ignoring the local cultural context and the specific needs of the caregivers. The expression "doctor-patient secret" communicated the discontent of the caregivers, who felt that they had to grapple with complex situations yet with limited information. In this way the medical approach alienated the caregivers, whose expectations to be informed about the nature of the illness were usually not met.

It is recommended that health professionals adopt ways of dealing with HIV/AIDS which empower families to deal with the epidemic competently and without exposing family caregivers to the risk of infection, and that would incorporate the potential caregivers in the doctor-patient relationship. There is an indication that patients benefited when doctors shifted from their conventional role as 'curers', and helped the patients and family members to deal HIV/AIDS openly, but there is a need to systematically study how various circumstances, including the age of patients and caregivers and their relationships, influenced the health care professionals' decision about what was in the best interest of their patients. In the same way that delay in seeking medical care is undesirable, delay in the provision of lay care should be avoided.

Although the findings were based on a small sample, the external validity of these findings emanates from the 'thick description' of the care context and detailed quotes of the caregivers. The findings of the study will provide the basis for future research in comparable situations in sub-Saharan Africa. There is a knowledge gap regarding the demand and utilisation of inpatient care services as a resource for home-based care. These findings suggest that while the primary goal of home-based care is reduction of hospitalisation, there is also a risk that reduced utilisation might erroneously be attributed to functioning home-based care programmes, while in actual fact it conceals the unmet needs of the patients and their caregivers, especially in the context of inadequate medical treatment, including poor access to antiretroviral therapies.

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