

Ambiguous diagnosis, futile treatments and temporary recovery: Meanings of medical treatment among HIV/AIDS family caregivers providing care without ARVs

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Abstract

The capacity of countries with high HIV and AIDS prevalence to provide antiretroviral treatment and care for all people who need support remains a public health challenge. In Lesotho, there are improvements in this area but the high proportion of people who need ART yet they do not receive treatment suggests that many HIV-infected people continue to depend on medicines that treat opportunistic infections. The objective of the article is to explore caregivers' experiences with diagnostic procedures and outcomes, prescriptions and treatment outcomes when ARVs were unavailable. A phenomenological design using in-depth face-to-face interviews was used to obtain the experiences of 21 family caregivers about caregiving, including access to and use of medical treatments. Caregivers' experiences indicate that most of the consulted health professionals provided vague and inconsistent diagnoses while the medication they prescribed failed to treat most of the symptoms. Unavailability of medicines that control pain and symptoms effectively continues to be a prominent feature of HIV and AIDS home-based caregiving in Lesotho. It is recommended that health professionals should facilitate disclosure of HIV diagnosis to family caregivers to assist them to understand unstable treatment outcomes; and policy makers should strengthen home-based care by developing policies that integrate palliative care into HIV and AIDS care.

Keywords: family caregiving, medicines, HIV diagnosis, opportunistic infections, treatment outcomes, Lesotho.

Résumé

La capacité des pays disposant d'une forte prévalence du VIH et du Sida à fournir un traitement antirétroviral et des soins à toutes les personnes ayant besoin d'un soutien reste un défi de santé publique. Au Lesotho, des progrès ont été accomplis dans ce domaine, mais la forte proportion de personnes ayant besoin d'ART mais n'y ayant cependant pas accès suggère que de nombreuses personnes séropositives continuent à dépendre de médicaments traitant les infections opportunistes. L'objectif de cet article est d'étudier les expériences des aidants en matière de procédures de diagnostic et de résultats, de recommandations et des résultats du traitement administré en cas d'indisponibilité des ARV. Une approche phénoménologique faisant appel à des entretiens approfondis en face-à-face a été utilisée afin d'obtenir les expériences de 21 aidants de familles en matière d'administration de soins, et notamment en matière d'accès aux traitements médicaux et de leur utilisation. Les expériences des aidants indiquent que la plupart des professionnels de la santé consultés ont émis des diagnostics vagues et incohérents, et les médicaments prescrits ne pouvaient traiter la plupart des symptômes. La non-disponibilité de médicaments contrôlant la douleur et les symptômes continue à constituer une caractéristique essentielle de l'administration de soins pour le VIH et le Sida à domicile au Lesotho. Il est recommandé que les professionnels de la santé facilitent la divulgation du diagnostic sérologique aux aidants familiaux afin de les aider à comprendre les résultats associés à un traitement instable; les décideurs devraient également renforcer les soins à domicile en développant des politiques intégrant les soins palliatifs à la prise en charge du VIH et du Sida.

Mots clés: soins familiaux, médicaments, diagnostic du VIH, infections opportunistes, résultats du traitement, Lesotho.

Introduction

The capacity of countries with high HIV and AIDS prevalence to provide antiretroviral treatment and palliative care for all people who need support during the different stages of the disease remains a public health challenge. Lesotho, a small sub-Saharan country with a fragile economy and a population of 1.8 million people has seen one of the highest HIV and AIDS prevalence rates in the history of the epidemic, estimated at 31% in 2003 and currently 23%. As with other sub-Saharan Africa countries, antiretroviral therapy (ART) was often not available to people

who needed treatment, many infected people fell ill unaware of their HIV serostatus and mortality was high. Today this picture has changed significantly; there has been a rapid scaling-up of HIV counseling and testing and ART in the region in general. The change from non-ART treatment to reaching more than a quarter of the population in need of ART, about 28% (WHO, UNAIDS & UNICEF, 2008) in less than a decade has produced significant public health benefits (UNAIDS, 2009). In Lesotho only about one quarter (26%) of more than 80 000 adults who need ART receive it

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(Cohen, Lynch *et al.*, 2009; Kell & Walley, 2009). Without universal access to comprehensive treatment many HIV-infected people in need of ART continue to depend on medicines intended to treat opportunistic infections only and are likely to experience pain and symptoms that diminish their quality of life and that of their family members (Kell & Walley, 2009).

The development of scientific practices that 'objectively' lead to diagnosis of disease as a pathological condition within the body became prominent in medical practice in the nineteenth century, and is one of the achievements of hospital medicine (Armstrong, 1995; Brown, 1995; Lachmund, 1998; Lupton, 2003; Van der Geest and Finkler; 2004). Medicines are important for treating both acute and chronic symptoms and the meanings attached to medicines are integral to the doctor-patient relationship. When people experience severe illness they expect doctors to apply expert knowledge to provide objective diagnosis and prescribe effective medicines and be available to support the family members, especially where there is uncertainty. Generally, when members of families seek medical treatment for a relative, 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 & Waddell, 1998). In fact, the two are considered as the medical tasks that matter to doctors during clinical consultation (Gwyn, 2002). 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 role of the doctor. Over time, medical knowledge was regarded to have provided certainty with some disease brought under control through prevention and therapies and their threat to life diminished even if cure was not attainable (Mantovani, Anker, Morley, Scevola, Yeh, Inui *et al.*, 2006).

In the case of HIV and AIDS there are no curative therapies, and outcomes of medical treatments that do not include ARVs produce unique experiences for caregivers since they may not have optimal palliative effect. The understanding that doctors prescribe medicines that lead to positive treatment outcomes is challenged and the meanings of medicines as modern artefacts that ameliorate suffering are fundamentally contested by lay people. This ability is further hindered by the tendency of HIV to trigger other ailments, leading to co-morbidity and the need to manage illness with equally sophisticated therapies, as is the case with HIV-TB co-infection (Lawn, Wood, De Cock *et al.*, 2010).

This article describes experiences of family caregivers of HIV and AIDS patients with medicines before the government of Lesotho made ARVs available in the public health sector following the interpretive perspective which seeks to understand 'what meaning and what significance the social world has for the people who live in it' (O'Brien, 1993:7). The article analyses the meanings of clinical consultations as encounters that entail various forms of social actions by health care practitioners including diagnosis, communication about diagnosis and medical prescriptions. The analysis of meanings of medical treatment for family caregivers takes into account lack of HIV counselling and testing services, HIV serostatus confidentiality, ART unavailability and high dependence on family members for provision of home-based care that mostly took place with limited professional support for

families (Levine, 1991; Makoae, 2009; Makoae & Jubber, 2008; Mupedziswa, 1998; Van Dyk, 2001). These contextual factors influenced communication between health care professional and family caregivers in unusual ways. These interactions and outcomes of treatment constantly changed the meanings of medicine with its underlying traits of certainty, control, orderliness and precision promised by science held by most caregiver. Although the context of HIV and AIDS care is changing, this analysis sheds light on some of challenges that may prevail in resource-constrained care contexts but also encourages future research on how reported experiences have changed in situations where doctors can prescribe ART.

Medical care in chronic illness

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. Diagnosis techniques can provide a 'categorical decision' about a clinical condition related to disease but more often clinicians apply 'evidential reasoning' with acceptable limitations to reach diagnostic decisions about clinical situations (Szolovits & Pauker, 1978). However, that medical decisions are made along a continuum of certainty is taken for granted in ordinary clinical consultations. Generally, when 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 & 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 chronic illnesses and HIV and AIDS there are no curative therapies, and care outcomes of medical treatments which do not include antiretroviral drugs are likely to produce unique experiences for those who provide care. Apart from the psychosocial consequences of HIV diagnosis, physical pain is a common aspect of the AIDS disease and it is one area known to be poorly managed in most sub-Saharan countries with high AIDS prevalence (Kell & Walley, 2009). Furthermore, Karasz, Dyche & Selwyn (2003:1611) rightly recognise that in the context of chronic diseases and the HIV and AIDS 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.

There have been significant positive changes in high-income countries of the West, including Australia, due to the introduction of AZT in the late 1980s and of the highly active antiretroviral therapy (HAART) in the 1990s. As a result doctors began to salvage the medical imagery in the management of AIDS-related illness (Carricaburu & Pierret, 1995; Karasz *et al.*, 2003; Persson, 2004). On the contrary, Liddell, Barrett & 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 the hegemonic status of biomedicine ironically subverted the cultural responses to the disease. The doctors constantly realise

the ineffectiveness of their treatments and they are also aware of the stringent economic measures taken by planners to contain treatment costs. However, the literature is limited in terms of providing understanding of the experiences of family caregivers with medical interventions in low-resource contexts, yet there is evidence that treatment inadequacies are not only due to lack of ARVs. Sub-Saharan Africa countries with high TB prevalence and risk of HIV co-morbidity have not up-scaled TB interventions recommended globally for preventing and controlling related morbidity and death – the WHO *Three Ts* or isoniazid preventive treatment, intensified case finding for active TB, and TB infection control (WHO, 2008) despite the limited effectiveness of the directly observed therapy – DOT (Lawn, Wood, De Cock *et al.*, 2010).

Emotional distress is common when a family member suffers from a life-threatening illness. This situation means that the patients and their families will find support of the physician indispensable as they try to cope with the disease. This tendency has been studied extensively in cancer care contexts (Gotay, 1996; Blanchard *et al.*, 1996; Strasser, 2003; Strasser, 2006) but it has also been reported with HIV and AIDS care (Nilmanat & Street, 2004). In the context where health care is organised on the basis of public hospitals, outpatient departments provide the bulk of routine services for the patients and health professionals can contribute to family members' quality of life by controlling clinical conditions that cause severe distress. 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).

Methods

Study design and data collection

This article analyses the findings of a larger qualitative study conducted in 2004 on the experiences of family caregivers who provided home-based caregiving to relatives diagnosed with HIV infection or AIDS illness at two hospitals in Lesotho (Makoae, 2009; Makoae, 2011; Makoae & Makoae, 2008). In-depth face-to-face interviews were conducted with family caregivers. They were encouraged to talk about anything pertinent in the way that they experienced caregiving including access to and use of medical treatments. Since the intention of the study was to identify experiences which the caregivers perceived as significant and the meanings of such experiences, the phenomenological design (Moustakas, 1994; Creswell, 1998) was adopted.

The interviews were guided by the interviewer after asking the participants to describe what providing care for patient X entailed, but were allowed to proceed in a conversational and informal manner. This approach is in accordance with the *epoché* – a requirement in phenomenological research that states the researcher must acknowledge his/her assumptions concerning the phenomenon that is being investigated and then suspend such preconceptions (Moustakas, 1994; Creswell, 1998). The interviews generated first-person descriptions of life experiences in caregiving including the use of health services and medicines (details of the method in Makoae, 2009).

Setting

The study area comprised communities that received healthcare services from the two hospitals in Berea District, Lesotho. At the time, the Maluti Adventist Hospital prescribed ARVs on the basis of a patient's ability to pay for laboratory tests and ARVs, while the government healthcare policy did not provide for ARVs in public institutions including the Berea Government Hospital.

Sampling procedure

The family members were identified through the assistance of HIV/AIDS counsellors at the two hospitals. The counsellors identified potential interviewees and accompanied the researcher to make first contact with the caregivers and to solicit consent. Verbal informed consent was obtained from the family caregivers in the presence of the care-recipients, where the latter were alive. Purposive sampling was used to select the caregivers using the following criteria: a) a current or ex-caregiver who provided care at home for a family member diagnosed HIV-positive at one of the two hospitals; b) caregiving was provided after 2002 when the government policy on home-based care was pronounced; c) current caregivers who had spent at least one month as caregivers and had acquired some insights with what was involved in home-based care; and, d) willingness to be interviewed at length using a tape-recorder.

Sample

Twenty-one family caregivers were interviewed. The majority of the caregivers were females ($n = 16$ females and 5 males). They were aged between 23 and 85 years and they cared mainly for youths and adults, although two care-recipients were children under age 12. The caregivers included some who had exited the role because a patient had died; also, some patients died during the fieldwork, leading to caregivers' postponement or withdrawal from the interviews. Each caregiver was in a close family relationship with the care-recipient (for example, parent, child, spouse, grandmother, sibling, aunt, uncle, and in-laws). However, only three caregivers had been informed by a healthcare professional about the HIV-positive status of their patient.

Ethical considerations

The research questions and the methods of data collection were shared with the relevant authorities. The study proposal was submitted for approval to the then Lesotho AIDS Programme Coordinating Authority (LAPCA) which was a body mandated to authorise HIV and AIDS research in the country. After obtaining permission from the hospital authorities, the health workers provided input to the study approach by advising about preventing unintended disclosure of the patients' HIV status during the study because the counsellors were aware that many patients would not have disclosed their status to family members including their caregivers. The counsellors volunteered to introduce the researcher to the patients who were in the respective hospitals' register of home-based patients. The study was broadly introduced as intended to obtain caregivers' experiences about providing care for relatives at home, without specifying the HIV status of the patients during the interviews. The family members who were identified by the counsellor or patients as responsible for caregiving were informed by the researcher that she was a student and the research was for academic purposes and the

findings would be published without revealing their identity and were asked to allow the use of a tape recorder. The caregivers were also informed that their participation in the study was voluntary and that they were free to withdraw if necessary, without consequences. After making initial contact with the caregivers, only the researcher visited the caregivers to establish rapport and subsequently to conduct interviews. During data collection the tapes were securely stored in the researcher's office and were destroyed after transcription while the electronic version of data is stored in a personal computer.

Data analysis

The researcher transcribed the interviews verbatim and translated the transcripts from Sesotho to English. This was followed by reading the transcripts individually in order to gain a general sense of the descriptions about medical care. By reading sentence by sentence, the meanings of the significant statements about seeking medical care and experiences with various aspects of the medical treatment were identified and categorized according to themes and sub-themes. Three broad themes were process of obtaining treatment, forms of medical treatment, positive experiences and negative experiences while the sub-themes included consulting doctors, diagnosis, prescription and treatment outcome. These were further arranged into meaning units such as ambiguity, inconsistency, symptom improvement and hope.

Findings

Ambiguous and inconsistent diagnosis

The established role of medical professionals to provide medical diagnosis that shed light on symptoms was questioned when diagnosis was perceived as imprecise or contradicted common knowledge. Many caregivers were articulate and familiar with various diagnostic procedures (X-rays, pathology tests and analysis of bodily substance such as blood and sputum) conducted during medical consultations, some of which they specifically requested. It was uncommon for caregivers to receive HIV diagnosis after screening:

When the nurse told me HIV I felt confused. I looked at her and I think she 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).

Instead, doctors were perceived to provide unsatisfactory explanations for experienced illness, leading to the caregivers consulting other doctors seeking alternative diagnosis.

I took her to see many doctors ... Dr M talked about the pain at the back and in the chest ... The doctor did not say what the cause of the pain was ... I took her to the hospital and they mentioned the same problem, the chest ... (Father 2).

Since she fell ill, it has been her and I trying this and that. I took her to 'X' hospital several times and it was not clear to the doctors what was happening and I paid for her medication, yet they could not tell me. I took her to 'Y' hospital, even there they could not diagnose her (Father 1).

Various diagnostic procedures did not lead to explicit diagnosis and some of the caregivers doubted the claim that doctors were unable to detect the underlying causes of illness when symptoms were noticeable:

I don't believe anyone who goes to the doctor and comes back and say: a doctor cannot see what the problem is. Is there such a thing? Even I, when sick, the doctor is able to tell me ... I saw some of the signs but I am not a doctor r..., but I would not buy the TB story (Grandmother).

When I had taken him there [hospital] they told us they could not detect what his illness was. The doctor said he could not 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 x-ray because he was complaining about the pain in the chest ... (Father 3).

Some doctors were reported to have communicated diagnoses which the caregivers found inconsistent with common knowledge about some diseases and their prognosis, making the caregivers doubt such diagnosis.

I was suspicious and I said, 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?' I saw the sputum and said, no, no, I don't see how this could be ulcers ... I thought about TB but the doctors were saying ulcer ... Who am I to question what doctors and nurses who have been trained for years say? (Mother-in-law).

Perceived appropriateness of prescriptions

Caregiving experiences tended to be influenced by whether the patients could obtain medication or not. The doctors maintained the traditional role of prescribing medicines even when the caregivers expected more or were not convinced that the prescriptions would improve the patients' condition. Different caregivers reported patients receiving some form of prescription when they consulted health facilities:

At the hospital they gave her medication, tablets and something to apply on the wounds and she recovered (Mother 3).

She was never hospitalised ... They gave her tablets again (Mother 2).

They just gave him tablets (Father 2).

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 ... (Aunt).

Disillusionment with treatment was inevitable when the caregivers were aware from the beginning that the patients were not prescribed optimal treatment. Those who knew about the HIV

diagnosis were also aware that the patients were not prescribed ARVs. In one of the hospitals, the doctors assessed the financial ability of the households to sustain ARVs before they put patients on a non-ARVs treatment. Consequently, knowing that the patients were not receiving optimal medical care was distressing.

When you take someone to a 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 [ARVs] – 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 the other medicine separately ...? They said they cost a lot of money ... I was hurt ... this person goes to hospital but the hospital doesn't give her the medication 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...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 for HIV' explanation focused on the present and drew comfort from other factors including their spirituality, traditional medicine and other encouraging signals about the patients which suggested improvement. They hoped that the care-recipients would persevere until the time when ARVs would be 'available'.

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 (Aunt).

Our general approach is to give him the best that we can, sometimes even more than our own children because we realise 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 doctor The doctor could not stop marvelling this boy ... It is such things that give me courage (Uncle1).

I personally had hope that maybe 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 ... (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. Sometimes they were concerned that the doctors misdiagnosed the symptoms and therefore prescribed incorrect 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 initial 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 and atypical TB dose which a doctor prescribed against her objection. She blamed a doctor for negligence because he ignored her opinion regarding 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).

[They gave him] tablets which did not help him because as he was taking them he continued to complain about these pains (Father 2).

The caregivers who knew that the care-recipients were HIV- and AIDS-positive tended to seek medical treatment for various symptoms including TB treatment for free and generally enjoyed tremendous support from the health professionals. For example, unlike patients 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.

He's not on antiretroviral drugs. What I realise 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. 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 for 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).

Effects of medicines on symptoms

Irrespective of whether or not they knew about the HIV and AIDS status of the care-recipients, the caregivers expected the medicines prescribed by doctors to be effective. Others appreciated the fact that HIV and AIDS could not be cured but hoped that the

medicines would ameliorate severe symptoms. But more challenges were encountered when the caregivers did not understand the entire context of the symptoms including HIV diagnosis and the limits of available medication.

Symptoms improved

Indeed some caregivers observed significant positive changes when they administered specific medicines including traditional herbs. These changes were reduced illness episodes, severity of symptoms, improved physical appearance and independent functioning. The most important consequences of these changes were that hospital consultations ceased to be erratic; the patients 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 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 ... At the moment this feeling that he could die has subsided because he looks much better after he was prescribed these medicines. (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 ... 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).

... 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).

Health professionals were also reported to have explicitly or implicitly communicated hopelessness with the patients' situation at some point. Later, improvements were realised giving the caregivers some hope that the patients were 'cured' while also proving some of the doctors mistaken.

But as you can see she is much better because at that time she had lost so much weight ... I wish that doctor could see her because the nurse here was so surprised when she saw her last time ... She actually said it again that she did not believe that she would see her so health y... 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 ... (Mother3).

I did everything for her and there was a time when she really 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).

I realise 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).

The caregivers were hopeful about their caregiving situation because they either observed changes or received positive feedback from others who interacted with the care-recipients. Some caregivers had strong belief that the drugs which were known to be effective for the 'diagnosed' diseases, especially TB and symptoms such as diarrhoea would work. But such positive signs did not endure.

Negative experiences

In many instances the caregivers realised that the improvement with their relatives' symptoms were short-lived. The common experiences were symptoms that did not respond to medication, new complications while on treatment and relapse after what would have seemed as cure. Lack of improvement despite the patients' compliance with the prescribed treatment was observed with TB and other complaints, a situation which was perplexing since TB was generally known to respond to treatment well. Some doubted the authenticity of the 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.

Non-responsiveness to medication

It is now four months. But there is still no change. This is the thing I don't understand. Do you see me now? Can you believe that I was also on TB treatment ...? But I am well, now. 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).

I don't know the disease troubling this child. He is still on TB treatment but I don't see him improving ... I don't like it when someone is taking tablets every day, but you can't say you see change ... It is becoming common among our young people ... they are treated for TB but they don't get better, but very old men, when they are discharged they are cured. I don't understand the diseases of today (Uncle2).

Sometimes subsequent episodes of illness tended to be more severe than previous ones, and in some instances calm periods were soon followed by death. Sometimes the caregivers firmly believed that doctors made wrong prescriptions for the patient and blamed them for the patient's death.

I was convinced that God ... was not taking her. I'm saying she had already resumed collecting her food parcels from the hospital: she was much better. 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).

Even trusted medicines failed to treat the caregivers' relatives yet they worked with similar symptoms in other people.

But there is nothing that can be done because there is no turning back, we are just watching things progress, 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 hospital are up and about and here he is. Now I don't know but it is still my wish that he gets better ... (Sister-in-law1).

New symptoms while on medication

There were occasions when the caregivers were aware that the patients experienced new conditions which they attributed to the prescribed medicines. Some medicines were believed to aggravate the symptoms and the doctors' intervention seemed ineffective.

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 ... she was panting with 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. We did not know what to do ... She cried and I pitied her. I felt pain because I could see this child was suffering ... (Mother3).

It became clear that the actual problem was in the chest, but 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 they would review her treatment. They 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. They changed her tablets and we would think that probably they would work, but no, they made her worse, there was no use, my child died ... (Mother2).

She is much better even though when she was discharged from the hospital after two weeks she developed these rashes. She was scratching herself and I tried to give her some herbs in addition to the ointment that they gave her at the hospital. I was hoping to force these rashes to come out of the skin ... I can see that they are beginning to subside even though I don't expect them to disappear immediately (Father1).

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 optimistic. Unexpected new complications following perceived improvement devastated family members and rendered the search for the meaning of the illness futile because the circumstances for relapse were inexplicable.

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 are not cured; this thing just lay low, hiding. It didn't take long before she started to cough again ...

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 helplessness was particularly experienced if the patient was on medication and there was no reason to doubt their adherence; these were some of the puzzling and discouraging moments:

I had really lost hope ... we took him to hospital and he stayed there for a very long time, about a month because he needed to recover. Then we realised that this disease is getting worse even though he is taking medication so faithfully ... (Sister-in-law1).

She was later discharged and she went home, she was taking 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, she 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 don't know what triggered this [severe cough]. 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 ... I really don't know what kind of a battle we are fighting, I don't understand because she was taking her TB tablets... (Father1).

Discussion

The caregivers' experiences with medical treatment reveal their 'lifeworld' of caregiving as mediated by the practices of health professionals and by medicine. They indicate that caregivers had strong beliefs that doctors' actions including diagnosis and prescription of medicine as well as the treatments were vital in caregiving. However, most of the caregivers were not aware of the limitations of the medical treatment received by their relatives. Although there were different degrees of optimism about the expected outcomes of medicines, they expected medication to ameliorate the symptoms. This understanding created expectations about the role of the doctors and the function of the techniques they used for treatment. When HIV and AIDS were acknowledged, the caregivers' coping mechanism was to remain hopeful about the future possible medical developments which would lead to availability of effective treatment while their role was to manage the symptoms with available therapies to prolong the patients' life.

Irrespective of the circumstances surrounding experiences with the symptoms, the caregivers intuitively considered medicines key to improving the situation of their sick relatives and doctors were expected to play their traditional role in illness experience – diagnosis and prescription. Therefore, it was beyond the caregivers' comprehension but also disappointing that some medical experts failed to provide diagnosis with certainty, sometimes simply confirming the symptoms as the 'reason' for illness. This was contrary to the success of modern medicine which has been linked to its ability to make interventions that 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). Various techniques used to examine the patients were expected to provide absolute 'truth' or what Szolovits & Pauker (1978) refer to as categorical diagnosis. Sometimes the caregivers believed that they had a better explanation for the symptoms than what clinical diagnosis offered.

After repeated consultations which sometimes entailed reviewed treatments it became apparent to many caregivers that doctors prescribed ineffective medicines. Some prescriptions were viewed as not credible. Those who were aware of the positive HIV serostatus of their relatives were convinced that the medicines would not optimally control the illness. The perception that some doctors did not follow established treatment protocols was a source of distress amidst the caregivers' perceived powerlessness in clinical settings. For instance, the caregivers were convinced that some of the treatments were 'useless' since they did not match the clinical diagnoses. Van der Geest & 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. Also, lay people mainly consult health care facilities to obtain medicines but usually they have 'clear ideas of how the drugs should look and what effects they should have' (Sachs & Tomson, 1992: 314). Health promotion and public health placed tuberculosis in the public domain and community participation empowered members with knowledge about the symptoms and management of TB. Seemingly, attempts to 'gloss-over' the HIV diagnosis with socially acceptable disease labels including TB could reverse these gains and create chaotic help-seeking behaviour.

The absurdity of the norm of prescribing in the studied caregiving contexts was also obvious where the doctors disclosed the HIV and AIDS status of the patients but indicated that there was no treatment for the disease or failed to prescribe optimal treatment due to economic considerations. The caregivers perceived it anomalous that doctors who knew what treatment would work consciously and repeatedly prescribed medical treatment on account of cost. Such practices defied their assumptions about the benevolence of doctors. Although misleading, it was easier for the caregivers to accept that HIV treatment was unavailable than to accept the cost-related explanation. The former gave the impression that the problem was universal while the latter bolstered feelings of deprivation or uncaring attitude of doctors which some inferred to HIV stigma. The predicament of family caregivers who cannot afford medical fees and as a result forgo biomedical drugs which they are told would treat the illness has been reported in sub-Saharan Africa (Bindura-Mutangadura, 2000).

Medical drugs have social meanings and are part of the social practice of biomedicine. Ordinarily, doctors 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 treatment for opportunistic infections suggested that since the treatments were not expected to provide optimal treatment, the prescription of drugs was mainly symbolic. 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 who are involved in the providing, administering and taking of the medicines (Whyte *et al.*, 2002: 31). Sachs' analysis of clinical encounters and prescribing behaviour in rural Sri Lanka indicated that 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 the caregivers as well as maintaining normality in medical encounters than as therapeutic technologies, especially when they were not palliative. 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, it would be abnormal for medical encounters to end without prescriptions (Sachs and Tomson, 1992) because medicines are integral to healing relationships.

Other medical interventions were perceived as inappropriate because they were inconsistent with the recognised treatment practices. This was mainly the case with TB prescriptions because many caregivers were familiar with the regimen and prognosis. Some doctors' prescription practices were interpreted as questionable leading to pessimism and suspicion about the intentions of such doctors. 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).

Mistakes and uncertainty are not usually mentioned in medical encounters, but the practices described in the study suggest 'faulty prescribing by professionals' (Whyte *et al.*, 2002). These practices indicated nuances of non-compliance on the part of health professionals. In other words, the experiences illustrated that non-compliance could not always be understood exclusively from the perspective which found blame in the patient – in this case the health professionals' behaviour was equally crucial in bringing about desired effects of medication. Sachs and Tomson (1992: 314) refer to Trostle's insightful characterisation of compliance as an ideology which presupposes and rationalises 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). Some of the caregivers doubted health care professionals' commitment to providing solutions for the patients since some verbalised hopelessness about the patients' situation and the caregivers had misgivings with prescription

made. The significance of the support by health care professionals to family caregivers of chronically ill relatives has been noted in various contexts including mental illness (Magliano, Fiorillo, De Rosa *et al.* 2005) and cancer (Blanchard, Ruckdeschel & Albrecht, 1996; Thomas, Morris & Harman, 2002). Therefore, it was inevitable that the caregivers who were satisfied with the support from the hospitals would have positive experiences due of the stability and a 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) including its contribution to continuity of care for home-based patients (Makoae & Jubber, 2008).

Ultimately, the caregivers had poignant experiences with the outcomes of medical treatment. 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 their relatives, hence moments of pleasure and encouragement in their role, in many instances such outcomes were short-lived. For example, moments of improvement were transient; some of the symptoms improved, but others persisted while new complications emerged. The assumptions about the curative power of medicine in general and of specific treatments which the hospitals were known for were usually shattered. 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 *et al.*, 2002) especially communicable infections.

Although it is common knowledge, particularly in 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 ordinary members of society about the 'infallibility of modern medicine and the magical power of prescribed drugs' (Sachs & Tomson, 1992: 313). 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 & Whyte quoted in Hunte & Sultana 1992: 1385). Nilmanat & Street (2004) also 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 family members who assume the caregiving role at home were informed about the implications of these changes for caregiving, it was difficult to attribute patients' poor response to medical treatments to compromised immune system. Doubt was expressed about the health care professionals and not in relation to inevitable inefficacy of the medicines. The major contradiction, however, was that the participants in the present study experienced drug inefficacy at the time when improved HIV drugs saved lives in high-income countries thus producing positive care experiences

(Carricaburu & Pierret, 1995). Physicians' experiences with HIV following the development of HAART restored the 'myth of a good doctor' and improved the quality of life of HIV/AIDS patients who without this form of intervention could have died (Karasz *et al.*, 2003). Persson (2004) 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: 46, 47). Recent research indicates that expanding ART for free to people who are in need of it has curbed the problem of delay in seeking medical treatment and patients are initiated on treatment before they are too ill (Cohen, Lynch *et al.*, 2009) and that even with the advent of ART palliative care is necessary to minimise human suffering due to acute and chronic pain (Kell & Walley, 2009).

Conclusions

This article explored how family caregivers of HIV and AIDS patients experienced medical treatment by doctors in Lesotho before ART. The meanings that the caregivers had about doctors' actions and techniques of diagnosis, communication and prescriptions highlight some of the challenges that health care systems and doctors face in maintaining normality in their function in society where there is inadequate treatment for people living with HIV. Unavailability of medicines that control pain and symptoms effectively will continue to be a key aspect of home-based caregiving in resource-poor contexts including Lesotho before universal access can be attained. Health professionals could enhance caregiving experiences by facilitating disclosure to family caregivers, providing information about AIDS co-morbidity and helping the caregivers to understand the limitations of available prescriptions instead of glossing over HIV diagnosis. Policy makers need to consider developing policies and guidelines for availing drugs that control pain for patients in home-based care. It is not clear how two decades of perceived ineffectiveness of the health system could have affected the imagery of health professionals and hospitals in the country. Nevertheless, health promotion strategy should not disregard the implications of this experienced change for services use, and clear messages that treatment was currently available to few people only as well as the benefits of treating opportunistic infections should be sustained. There is a need to intensify 'health literacy' among family caregivers to enable them obtain, process and understand the evolving health information and clinical services needed to make appropriate health decisions in home-based care. Future research could assess how family caregivers' experiences are being transformed with the availability of ART.

References

- Armstrong, D. (1995). The rise of surveillance medicine. *Sociology of Health and Illness*, 17(3): 393-404.
- Bindura-Mutangadura, G. (2000). HIV/AIDS, poverty, and elderly women in urban Zimbabwe. *Southern African Feminist Review*, 4(2): 93-105.
- Blanchard, C. G., Ruckdeschel, J. C. & Albrecht, T. L. (1996). 'Patient-family communication with physicians'. In Baider, L., Cooper, C. L. and Kaplan De-Nour, A. (eds). *Cancer and the Family*. New York: John Wiley & Sons. Pp. 369-387.
- Brown, P. (1995). Naming and framing: The social construction of diagnosis and illness. *Journal of Health and Social Behaviour*, Extra Issue, 34-52.
- Bury, M. (1997). *Health and Illness in a Changing Society*. London: Routledge.
- Carricaburu, D. & Pierret, J. (1995). From biographical disruption to biographical reinforcement: the case of HIV-positive men. *Sociology of Health*

and Illness, 17(1): 65-88.

Cohen, R., Lynch, S., Bygrave, H., Eggers, E., Vlahakis, N., Hilderbrand, K., Knight, L., Pillay, P., Saranchuk, P., Goemaere, E., Makakole, L. & Ford, N. (2009). Antiretroviral treatment outcomes from a nurse-driven, community supported HIV/AIDS treatment programme in rural Lesotho: observational cohort assessment at two years. *Journal of the International AIDS Society*, 12:23

Crawford, R. (1994). The boundaries of the self and the unhealthy other: reflections on health, culture and AIDS. *Social Science & Medicine*, 38(10): 1347-1365.

Creswell, J. W. (1998). *Qualitative Inquiry and Research Design: Choosing Among Five Traditions*. Thousand Oaks, CA: Sage Publications.

Dworzanowski, B. (2002). Caring for people dying of AIDS: lessons learnt from hospices. *Society in Transition*, 33(3): 420-431.

Gotay, C. C. (1996). 'Cultural variations in adjustment to cancer'. In Baider, L., Cooper, C. L. and Kaplan De-Nour, A. (eds). *Cancer and the Family*. New York: John Wiley & Sons. Pp. 31-52.

Gwyn, R. (2002). *Communicating Health and Illness*. London: Sage Publications.

Hatt, G. (1998) 'Uncertainty in medical decision-making'. In Petersen A. and Waddell C. (eds). *Health Matters: Sociology of Illness, Prevention and Care*. Buckingham: Open University Press. Pp. 223 - 239.

Hunte, P. A. & Sultana, F. (1992). Health-seeking behaviour and the meaning of medication in Balochistan, Pakistan. *Social Science and Medicine*, 34(12): 1385-1397.

Karasz, A., Dyche, L. & Selwyn, P. (2003). Physicians' experiences of caring for late-stage HIV patients in the post-HAART era: challenges and adaptations. *Social Science and Medicine*, 57, 1609-1620.

Kell, M.E. & Walley, J.D., (2009). Palliative care for HIV in the era of antiretroviral therapy availability: perspectives of nurses in Lesotho. *BMC Palliative Care*, 8:11 doi:10.1186/1472-686X-8-11.

Lachmund, J. (1998). Between scrutiny and treatment: Physical diagnosis and restructuring of 19th century medicine practice. *Sociology of Health and Illness*, 20(6): 779-801.

Lawn, S.D., Wood, R., De Cock, K. M. et al. (2010). Antiretrovirals and isoniazid preventive therapy in the prevention of HIV-associated tuberculosis in settings with limited health-care resources. *The Lancet Infectious Diseases*, 10(7): 489-498

doi:10.1016/S1473-3099(10)70078-5

Levine, C. (1991). 'AIDS and changing concepts of family'. In Nelkin, D, Willis, D.P. and Parris S.V. (eds). *A Disease of Society: Cultural and Institutional Responses to AIDS*. New York: Cambridge University Press. Pp. 45-70

Liddell, C., Barrett, L. & Bydawell, M. (2005). Indigenous representations of illness and AIDS in Sub-Saharan Africa. *Social Science and Medicine*, 60, 691-700.

Lupton, D. (2003). *Medicine as Culture: Illness, Disease and the Body in Western Societies* (2nd ed). London: Sage Publications.

Magliano, L., Fiorillo, A., De Rosa, C., Malangone, C., Maj, M. et al. (2005). Family burden in long-term diseases: a comparative study in schizophrenia vs. physical disorders. *Social Science and Medicine*, 61, 313-322.

Makoae, M. (2011). Food meanings in caregiving trajectories: rituals, optimism and anguish among AIDS caregivers in Lesotho. *Psychology, Health & Medicine*, 16(2):190-202.

Makoae, M.G. (2009). The phenomenology of bodily care: caregivers' experiences with AIDS patients before antiretroviral therapies in Lesotho. *African Journal of AIDS Research*, 8(1): 17-27.

Makoae, M.G. & Jubber, K. (2008). Confidentiality or continuity? Family caregivers' experiences with care for HIV/AIDS patients in home-based care in Lesotho. *Journal of Social Aspects of HIV/AIDS*, 5(1): 36-46.

Mantovani, G., Anker, S.D., Morley, J.E., Scévola, D., Yeh, S.-S., Inui, A.,

Fanelli, F. R. & Schuster, M.W. (eds) (2006). *Cachexia and Wasting: A Modern Approach*. Spinger: Italy.

Moustakas, C. (1994). *Phenomenological Research Methods*. Thousand Oaks: Sage.

Mupedziswa, R. (1998). AIDS in Africa: The social work response. *Journal of Social Development in Africa*. Harare: School of Social Work.

Nilmanat, K. & Street A. (2004). Search for a cure: narratives of Thai family caregivers living with a person with AIDS. *Social Science and Medicine*, 59, 1003 - 1010.

O'Brien, M. (1993). 'Social research and sociology'. In Gilbert, N. (ed) *Researching Social Life*. Sage: London.

Persson, A. (2004). Incorporating Pharmakon: HIV, medicine, and body shape change. *Body and Society*, 10(4): 45-67.

Peterson, A. & Waddell, C. (1998) (eds). *I Health Matters: Sociology of Illness, Prevention and Care*. Open University Press: Buckingham.

Ross, F. M. (1991). Patient compliance - whose responsibility? *Social Science and Medicine*, 32(1): 89-94.

Sachs, L. (1989). Misunderstanding as therapy: Doctors, patients, and medicines in a rural clinic in Sri Lanka. *Culture, Medicine and Psychiatry*, 13, 335-349.

Sachs, L. & Tomson, G. (1992). Medicines and culture - a double perspective on drug utilization in a developing country. *Social Science and Medicine*, 34(3): 307-315.

Sanders, L. M., Thompson, V.T., & Wilkinson, J. D. (2007). Caregiver Health Literacy and the Use of Child Health Services. *Pediatrics* 2007; 119; e86-e92 DOI: 10.1542/peds.2005-1738 (Accessed on 23 July 2008)

Strasser, F. (2003) Eating-related disorders in patients with advanced cancer. *Support Care Cancer*, 11:11-20. DOI 10.1007/s00520-002-0391-y

Strasser, F. (2006) The silent symptom early satiety: a forerunner of distinct phenotypes of anorexia/cachexia syndromes. *Supportive Care in Cancer*, 14(7): 689-692, DOI: 10.1007/s00520-006-0061-6

Stimson, G. V. (1974). Obeying doctors' orders: a view from the other side. *Social Science and Medicine*, 8, 97-104.

Szolovits P. & Pauker, S.G. (1978) Categorical and probabilistic reasoning in medical diagnosis, *Artificial Intelligence*. 11, 115-144.

Thomas, C., Morris, S. M. & Harman, J. C. (2002). Companions through cancer: the care given by informal carers in cancer contexts. *Social Science and Medicine*, 54, 529-544.

UNAIDS (2009). *AIDS Epidemic Update*. Joint United Nations Programme on HIV/AIDS (UNAIDS) and World Health Organization (WHO). Geneva. http://data.unaids.org/pub/Report/2009/JC1700_Epi_Update_2009_en.pdf (Retrieved: 6 October 2010).

Van der Geest, S. & Finkler, K. (2004). Hospital Ethnography: introduction. *Social Science and Medicine*, 59(10): 1995-2001.

Van der Geest, S. & Whyte, S. (1989). The charm of medicines: metaphors and metonyms. *Medical Anthropology Quarterly*, 3(4): 345-367.

Van Dyk, A. (2001). *HIV/AIDS Care and Counselling: A Multidisciplinary Approach*. (2nd ed). Cape Town: Pearson Education South Africa.

WHO (2008). WHO Three 'I's meeting: intensified case finding, isoniazid preventive therapy and TB infection control for people living with HIV. Report of a joint WHO HIV/AIDS and TB Department meeting 2-4 April, 2008, Geneva, Switzerland <http://www.who.int/hiv/topics/tb/3is/en/index.html> (Retrieved: 22 November 2010)

WHO, UNAIDS & UNICEF (2008). *Towards Universal Access: Scaling up priority HIV/AIDS interventions in the health sector - Progress Report 2008*. World Health Organisation, Geneva.

Whyte, S. R, van der Geest, S. & Hardon, A. (2002). *Social Lives of Medicines*. Cambridge: Cambridge University Press.

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