Abstract

It is generally assumed that caring is a substantial burden upon households afflicted by HIV/AIDS. However, as a 'private' household responsibility, little is known about the experiences of either those who provide the care, or those receiving care, despite the fact that the process may extend over several years and may have a greater impact upon the livelihood security and well-being of the household than the actual death of the ill person. Drawing upon data collected through solicited diaries, this paper explores how illness and the daily and long-term duties of caring amongst a sample of households in the Caprivi Region of Namibia impacts upon the physical and psychological well-being of ill people and their carers. While optimism and enhanced well-being was recorded during periods of illness remission, the nature of AIDS-related illness invariably results in periods of sickness and dependency, resulting in disempowerment and lowered self-esteem, and decreasing well-being amongst ill people. This paper argues that the increasing dependency of the ill person, widespread pressure to maintain household integrity through 'seeing for yourself' i.e. being self-sufficient, or at least contributing to reciprocal support networks, and the stigma attached to HIV/AIDS can result in considerable intra-household tension and breakdown of key social support networks.

Introduction

In the third decade of the epidemic, approximately 38 million people are thought to be living with HIV/AIDS, of whom 11.4 million reside in southern Africa (UNAIDS/WHO, 2004). Despite recent efforts to both increase HIV prevention and AIDS mitigation initiatives and to extend anti-retroviral treatment to people in low and middle-income countries, this is not yet being done on a scale that will halt or reverse the epidemic and it is clear that the impacts of HIV/AIDS will be felt for many decades to come. A growing literature demonstrates that people in areas of sub-Saharan Africa hard-hit by HIV/AIDS have experienced erosion of capital assets

through loss of labour of both the ill person and their carer, and through treatment and funeral expenses (Rugalema, 1999; Bond, 1999; Barnett & Blaikie, 1992). However, as a 'private' household responsibility (Baylies, 2002, Seeley, Kajura, Bachengana, Okongo, Wagner & Mulder, 1993), little is known about the experiences and perceptions of either those who provide the care, or those receiving care, despite the process often extending over several years and having a greater impact upon the livelihood security and well-being of the household than the actual death of the ill person. Drawing upon research undertaken in the Caprivi Region of Namibia, this paper provides an insight into the experiences and well-being of an illustrative sample of individuals and households confronted with long-term and stigmatised illness.

A subjective approach to understanding experiences and well-being recognises that social relations are lived and experienced through emotions (Bennett, 2004; Anderson & Bennett, 2001; Laurier & Parr, 2000; Widdowfield, 2000), and reiterate Sen's (1999:74) argument that well-being is largely determined by a person's capability to "choose a life one has reason to value." Rather than consider only income and material needs and the social relationships that are required to cope with the burdens of illness, it is therefore also important to consider the psychological state and subjective perceptions of people themselves (White & Pettit, 2004). Such an approach recasts "subjects of research as *persons* rather than as *patients*" (Kearns, 1995:252) enabling recognition of the often overlooked fact that a person with HIV/AIDS is still a person with livelihood and family responsibilities and associated emotions (Seeley & Pringle, 2001). While the term 'patient' is used in this paper, it is used in the context of these definitions. Ill-health and ill-being may therefore encompass not only the physical impacts of the 'disease', but a range of additional factors including exclusion, insecurity, powerlessness, self-respect and personal beliefs (Dean, 2003).

Interlinked with such feelings and of particular relevance in this paper is the impact of HIV/AIDS-related stigma. Drawing on deep-rooted fears and anxieties (Aggleton & Parker, 2002), stigma is defined by Goffman (1964:3) as a "process of devaluation", in which certain attributes are defined by others as discreditable or unworthy, resulting in the person stigmatised becoming 'discounted' or 'tainted'. Stigma may involve actions such as gossip, verbal abuse and distancing from the person with HIV/AIDS, can range from subtle actions to extreme degradation, rejection and abandonment (Bond, Chase & Aggleton, 2002) and can change over

time (Alonzo & Reynolds, 1995). While often dynamic and multi-dimensional, three broad types of HIV/AIDS-related stigma have been identified: i) self stigma, manifested in self blame and self-deprecation; ii) perceived stigma, regarding the fear people have around being stigmatised if they disclose their HIV positive status; iii) enacted stigma, when people are actually discriminated against due to their (actual or perceived) HIV status (Bond *et al.,* 2002). While all three types of stigma were evident in the study sites[1] and openly discussed during interviews and focus groups used in the wider study on HIV/AIDS impact, solicited diaries discussed in this paper focus mainly upon the stigma that ill people perceived was being directed against them and incidents of enacted stigma from within and beyond the household. This stigma was caused both by the tendency (within social and institutional contexts) to openly equate HIV/AIDS with immoral behaviour and by the terminal nature of the infection. However, in the study sites, stigma was also caused and exacerbated by prevailing attitudes towards dependence and reciprocity, with feelings of being tainted or discounted by others tending to increase at times when patients were too sick to be able to contribute to livelihood and familial activities. As Bond et al. (2002) make clear, it is important to contextualise this stigma and recognise that the fatigue and burden of care challenges the household's ability to provide treatment and support. That this burden often frustrates the best intentions of care and compassion should be borne in mind when interpreting the diary entries reported here.

Using solicited diaries in sensitive and stigmatised research

This research was conducted in the Caprivi Region, located in the far north-east of Namibia. Subsistence cultivation and livestock husbandry play a central role in livelihoods, although most households in the Caprivi are involved in a diverse array of activities to meet food and cash requirements. While strategically important for trade and transport, and a focal point of population movement across the southern African region, the Caprivi is one of the least developed regions in Namibia (Mendelsohn, Jarvis, Roberts & Robertson, 2002). This is due largely to decreasing life expectancy as a result of the region's poor health profile, caused and exacerbated by HIV prevalence rates of 43% (MOHSS, 2004).

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Research focusing upon the impacts of HIV/AIDS on physical and psychological well-being is usually (and understandably) confined to those who are aware of, and able to discuss their HIV status. Much of this research has been conducted in 'developed' countries, or amongst users of HIV/AIDS support groups (cf. Wilton, 1999; Friedland, Renwick & McColl, 1996) and focus has been placed upon the process of diagnosis, and the subsequent experience of 'living with HIV/AIDS'. Despite such high HIV prevalence, the acute stigma associated with HIV/AIDS and the fact that few people actually know their HIV status, meant that open discussion of HIV/AIDS in the Caprivi Region was only possible in a generalised, non-personal context such as focus groups. While the wider research study on HIV/AIDS impact adopted a multi-methods approach involving a livelihoods survey, repeat interviews, focus groups and participatory methods, it quickly became apparent that households in which a person was currently ill were under-represented in the study. One particularly successful method in ensuring that the study gave voice to such households was the use of solicited diaries, and these findings form the main focus of this paper.

The use of solicited diaries as a research tool has received scant attention within the social sciences. However, in line with Milligan, Bingley and Gatrell (2005) and Meth (2003), it is demonstrated here that such techniques offer valuable insight into the often hidden aspects of people's daily lives, and can facilitate collection of contextual in-depth data on sensitive and stigmatised issues. In this research, it was necessary to work with Home Based Care (HBC) groups[2] to identify households in which a person was currently ill, and to approach potential diary keepers. In each case, the HBC worker was already well known to the household, and was already visiting them to provide assistance. While the age and symptoms of ill people keeping diaries were consistent with recognised understandings of HIV/AIDS, stigma, low HIV testing levels and recourse to alternative illness narratives such as witchcraft, meant that in no case was this specifically stated as the cause of illness. Under such circumstances, it was not possible to explore how 'living with HIV/AIDS' specifically affected the experiences of the ill person or their carer. It was however, clear from the diaries that ill people felt that others perceived that AIDS was the cause of their ill health, thus HIV/AIDS became the dominant discourse shaping the experience of illness, influencing social relationships and the treatment, care and well-being of the sick person. At the time of the research, twelve people with AIDS-related symptoms

were receiving support from HBC workers in the study sites. All were approached to keep diaries, and although it was made clear that their participation was voluntary, all agreed to participate. However, three died before the diaries were initiated, one returned to her husband's village in a different area and one was prohibited from participating by his employer with whom he lived. It is recognised that different social groups may experience illness in different ways (Rugalema, 1999; Bharat & Aggleton, 1999). However, with one exception, all of the 'patients' keeping diaries in this research were women living in female-headed households. This is likely to have been influenced by the fact that households were identified through HBC workers. The gendered nature of caring in the Caprivi means that it is common for women to return to their own relatives for care, often their mothers who, if widowed, were likely to be disadvantaged in labour and resource assets and therefore, more reliant upon assistance provided by HBC workers. While the sample presented here precludes analysis of difference in the experiences of diverse social and economic groups, the fact they were dependent upon HBC workers suggests that they were less able to provide for the ill person than asset sufficient households, and it is quite likely that this situation will have influenced the experiences recorded in the diaries.

Diaries were kept by seven ill people and by their main carer for periods of one to six months. HBC workers made regular visits (usually several times a week) to households to provide assistance and to monitor the diary process. The act of diary keeping inherently raises issues of literacy. While literacy is widespread amongst younger generations in the Caprivi Region (86% amongst 15 - 40 years olds), it reaches only 21% amongst women over the age of 50 (National Planning Commission, 2003), who, in this research were the main providers of care. To ensure that illiterate people were not excluded, it was necessary in some cases for HBC workers to record diary entries on their behalf. This was the case for four carers and one patient and was discussed and agreed by each person before the diaries were started. In such cases, the diary entries were based on retrospective recall over a period of between one to four days.[3] This clearly raises issues regarding the private and personal nature of diary keeping and the manner in which the information was reinterpreted and represented by the HBC worker. In order to avoid misrepresentation, my translator and I visited each household whenever possible[4] to discuss, clarify and contextualise diary entries and ensure that diary entries recorded by HBC workers were authenticated by respondents. Coding and analysis of the diaries was undertaken

whilst in the field enabling rigorous cross checking of information and identification of themes common across the diary keepers. Diary extracts presented here were selected because they articulately represent these commonly held views. Diaries were recorded in the preferred language of each recorder, and those not written in English were translated by my interpreter who was literate in all six of the main languages used in the Caprivi.

It is important to recognise that diaries solicited specifically for research purposes are not private documents. Rather, "they are written with a particular reader and their agenda in mind" (Elliot, 1997: 9), a factor which may potentially bias the information recorded. While diary keepers were given a brief 'guide' regarding the type of information I was particularly interested in, namely their experiences, both positive and negative, of caring and illness, it was made clear that they were free to write what they wished. Diary entries varied, with some people writing on most days, enabling the dynamic caring and illness 'process' to be followed over time as it was experienced, while others provided a more retrospective account of some of their most memorable experiences. One advantage of the diaries was that they enabled the informant to set their own agenda and reveal information as they wished, although it is recognised that information could also be concealed. Rather than taking up significant chunks of their time as would have been the case with interviews, informants were able to write as little or as much as they liked at times that suited them. This was deemed an important consideration when these households already faced serious pressures upon their time and resources. In order to recompense those involved, people keeping diaries and the HBC workers 'supervising' the process were each paid N$100 (approximately £10) once the diaries had been collected. This was regarded as a small but significant sum of money, equating to the cost of a 25kg bag of maize meal. Given that diary keepers were asked to write about both the positive and negative experiences of illness and caring, it is unlikely that the payment would have had any significant influence upon the information recorded, although it is possible that it may have influenced the decision to participate by families experiencing financial stress.

The remission-recurrence cycle that characterises many AIDS-related illnesses meant that the health of those keeping diaries was variable. While some did not write during times when they felt ill, others reported that they found the process therapeutic, and that it relieved boredom and loneliness, particularly when other household

members were absent. Several also commented that it was easier to express their feelings in writing than verbally. A further advantage of the diaries was that 'supervision' from HBC workers meant the household received regular visits and assistance, and HBC workers reported that they were more aware of the needs of the household. Overall, the diaries appeared to be an appropriate and non-intrusive method of collecting sensitive information from otherwise hard-to-reach households. As Meth and Malaza (2003) point out however, diary keeping usually takes place in a private sphere, out of sight of the researcher, an issue that raises considerable debate in ethical terms. Attempts were made to ensure that diary keeping did not cause difficulties within the households concerned, although it was not possible to really determine the impact the process had on individual household members, and nor was it possible to provide emotional support at the time the often distressing accounts were being recorded. Such issues would need to be considered in greater depth before this method was used again.

Care in the Caprivi: contextualising the pressures of long-term illness

A household's ability to cope with the impacts of long-term illness and inter-linked shocks and stresses is influenced by the availability of social support provided through inter-household relationships. However, significant socio-cultural change since Independence in 1990, increasing economic heterogeneity, and an upsurge in witchcraft accusations were widely reported within this research to have resulted in a breakdown of familial support networks in the Caprivi Region. It was frequently stated that the welfare of the household was now considered a household responsibility, and that household members were expected to 'see for themselves' (be self-sufficient), before contemplating assistance from relatives or friends. While social pressures to 'see for yourself' are paramount, transfers within and between households continue to form a vital support network. Such transfers are however, rarely undertaken if they are not part of a reciprocal, although often unspoken arrangement, described by Van der Geest (2002:28) as the "silent book keeping of give-and-take." Being cared for is not then an automatic right, but a status requiring considerable investment. The long-term nature of HIV/AIDS therefore challenges the capability of the ill person both to reciprocate, and to actively contribute to the

household, thus compromising their identity and role within the household and the level of care provided to them.

The remission-recurrence cycle that characterises many of the opportunistic infections associated with HIV/AIDS means the intensity of caring duties varies over time. During periods of remission, it is not uncommon for the ill person and their carer to return to livelihood activities. However, as the immune-system is weakened and the person becomes increasingly ill, periods of remission become shorter, and eventually result in the patient becoming bed-ridden and dependent upon others for care. Because the ability of a household to access and mobilise assets is largely dependent upon the labour available to the household, the impact of illness upon a household's livelihood portfolio is significantly influenced by the role usually played by the carer and the ill person. Thus, if the ill-person had been a major contributor to the household asset base, their illness is likely to have a greater impact upon household livelihood security than if they were not, unless labour can be substituted or the activity adapted or diversified by other household members. Already labour-constrained households were therefore more adversely affected than households with sufficient labour, or transferable assets that could be used to pay for labour. The amount of time spent caring was influenced by the severity of the illness. However, as will be discussed, the necessity to continue with livelihood activities, and stigma and carer fatigue were also key factors.

As reported elsewhere in sub-Saharan Africa (cf. Radstake, 2000; Taylor, Seeley & Kajura, 1996), caring in the Caprivi is the duty of women. Caring duties involve preparing food and medicines, bathing the patient, cleaning sores, carrying immobile patients to the 'toilet' or to sit in the sun or shade, and washing soiled clothes and sheets. Such activities not only demand considerable physical effort, they require substantial periods of time away from livelihood and social activities that take place outside the courtyard. The unpredictable nature of the episodes of illness and remission meant that it was often difficult for households to plan their livelihood activities, leading to periods of uncertainty and insecurity. However, the necessity to ensure that at least the immediate food requirements of the household were met emerged as particularly influential in determining how livelihood and caring duties were prioritised.

Compromising caring and food security

In a situation in which it is deemed unacceptable to expect assistance from outside the household, it is not possible for illness-afflicted households to rely upon others to ensure the household is food sufficient. Instead, it is necessary to continue with livelihood activities in order to ensure at least some level of household food security is met. Because the majority of the agricultural workload is considered the responsibility of women, caring duties become a particular burden at times of the year when agricultural activities are intense. Diaries were kept between December and May, a period encompassing some of the most intense annual agricultural activities. In all cases, the carer continued to cultivate their crops whenever possible. However, in all diary keeping households, it was reported that the need to undertake caring duties meant that time was diverted away from agricultural activities, reducing the area cultivated and threatening food security. As the following diary extract demonstrates, the decrease in crops cultivated could also result in intra-household tensions and, through lack of money for school fees, could adversely impact on other household members, causing potential harm to future household livelihood security.

> The carer spent all day caring and is worried that she is too tired and hasn't been able to rest. The carer is angry with her daughter [the patient] because she didn't take her advice on how to live and now she is even suffering from hunger because she doesn't have enough time to work in her fields. She has been unable to pay school fees for the other children because due to caring they didn't manage to sell any crops. (Maureen, diary extract December 27th, 2003 – recorded by HBC worker).

Amongst those keeping diaries, this situation was exacerbated by poor harvests received in the three years prior to the research, through drought, flooding and/or caring activities. Few had harvested enough to cover household needs, and most had already sold assets or been forced to undertake piece work in order to meet their basic needs. While some households with sufficient labour and/or assets have flexibility to adapt their livelihood strategies to 'cope' with the burden of care with few adverse long-term livelihood impacts, labour and asset constrained households face considerable pressures to continue with key livelihood activities to maintain even a basic level of household food security. Under such circumstances, there were times

when the carer was forced to prioritise immediate household requirements over those of caring, particularly if without assets, the household was unable to generate cash to pay agricultural labourers or to purchase food. The difficulties facing the household therefore have significant repercussions for the well-being of the patient since the carer has far less time and resources to spend ensuring that even the basic needs of the patient are met.

Physical and psychological impacts of caring

As well as pressures to maintain food security, the physical and psychological pressures of care play a significant role in determining how HIV/AIDS impacts upon individual and household well-being. In their study in southern Malawi, Chimwanza and Watkins (2004) report that most carers did not consider care-giving a problem because the patients were close relatives. This view was supported in initial interviews in the Caprivi, and there was clear evidence that carers attempted to provide the best possible care under the circumstances. However, more in-depth interviews and the information recorded in the diaries revealed that over time, caring was seen as a burden which could impact detrimentally not only upon the household asset base but on intra-household relations, leading to ill-feeling and tensions, particularly between carer and patient. A key cause of tensions was the frequent mood changes of the patient and carer, based primarily upon the health status of the patient, with days of improved health reflected in optimism and increased psychological well-being and days of worsening health and recognition of the patient's vulnerable and dependent condition reflected in tensions, sadness, frustration and anger between the patient and carer.

During times in which the patient was feeling well, able to eat, or undertake livelihood activities, carers recorded relief that the patient may recover, and optimism for the future. However, carers suffered from the physical strain of caring, as well as the emotional consequences of their inability to provide adequately for their patient, and the failure of improvement in the patient's health. One of the most frequently reported impacts of caring was its effect upon the physical well-being of the carer with a number of them explaining that they were unable to eat, or ate only small amounts at times when the patient was seriously ill and themself unable to eat. This was partly due to the time expended on caring, and in cases of labour or asset

shortage, the lack of food availability. As Doris explains however, it is also a result of a psychological need to provide emotional and moral support to the patient.

> I don't feel well when my daughter is sick. I don't enjoy eating because I am feeling sorrow. It is only when she gets better that I can even eat normally. Even the children feel the way I'm feeling now and don't eat normally and don't do their activities well because of this. (Doris, diary extract May 17th, 2004).

Whilst carers felt able to eat at times when the patient was well enough to participate, their food consumption reportedly reduced for several months in the final stages of the illness. This is an issue of particular concern in AIDS cases in which opportunistic infections and stress can prevent the ill person from obtaining adequate nutrition (Haddad & Gillespie, 2001), and has significant implications for carers' physical well-being when illness is sustained over long-periods. During a community meeting, it was claimed that failure of a woman to reduce consumption during caring may be interpreted by others as displaying a lack of care and respect for the ill person, implying that the well-being of the carer and their ability to undertake livelihood activities is adversely compromised by socio-cultural expectation.

As prime carers, several women expressed anger that they were putting themselves at high risk of HIV infection in cases in which HIV/AIDS was known or suspected. This is possible in situations in which carers do not have the knowledge or resources to take necessary precautions, or where the stress of long-term care has led to carer's lowering their guard against infection. While this was not known to have occurred in the study sites, it was reported during focus groups that such perceptions could result in the carer and other household members distancing themselves from the ill person, leaving the patient increasingly isolated from their closest social support networks.

Tensions arose when the carer was unable to provide for a patient as they would wish. With higher than normal nutritional requirements (Haddad & Gillespie, 2001), a key cause of tension within households was the pressure to provide the 'special' foods that were craved by the ill person. Because of the relative inaccessibility and expense of these goods, considerable effort was required by households to provide them. However, AIDS-related infections can cause loss of appetite and difficulties with eating, thus it was not uncommon for patients to refuse

special foods once they had been purchased. This again was a cause of considerable friction within households, particularly when valuable time and resources had been spent procuring these goods. In households which could not afford to provide the foods requested Margaret's comment stresses how carers can become both frustrated and upset that they could not help the patient.

> Sometimes she [daughter] is in a bad condition and she chooses food that her heart needs. But myself I am poor and I cannot give her what she wants, and sometimes she spends the whole day without eating because I cannot afford what she wants to eat. (Margaret, diary extract February 26th, 2004)

At other times, when the household was under extreme pressure to undertake livelihood activities merely to subsist, and the demands of caring were overbearing, requests for special foods resulted in carers becoming angry and even neglecting the patient. The following extract was recorded by a HBC worker on behalf of a carer.

> The patient is complaining that his carer talks too much [complains] and he says that she is not taking proper care of him. The carer has gone to Ngoma to drink beer. She is angry with Stephen because he keeps asking for food which they cannot afford to buy. (Stephen, diary extract January 6th, 2004)

Caring which generates hope and support for an ill person can impact positively upon the well-being of the patient, providing them with a sense of self-worth, dignity and belonging (Skevington & O'Connell, 2003; Friedland et al., 1996). During the early stages of illness, it was not uncommon for several household members to provide assistance to the main carer, and for people outside the household to visit and occasionally help, providing goods such as food and sodas for the patient. Such actions not only assist the carer, but also demonstrate active inclusion of the ill person into the household and community. The long-term nature of HIV/AIDS and the importance attributed simultaneously to independence and reciprocity however, not only challenge the assumption of support from outside the household, but also support from within the household. Diaries demonstrated that while support was available in the early stages of illness, if the patient failed to get better, help tended to become steadily less forthcoming, leaving the main carer to cope with daily caring duties with little assistance at the same time as household resources were depleted

through treatment expenses and time spent away from livelihood activities. This resulted in the carer becoming lonely and isolated as they were less able to invest in social capital networks and in cases such as that described by Doris were adversely impacted by the stigma directed toward the ill person.

> No one has helped me care for my daughter. I feel discouraged by everyone in the community. Only sometimes the church members will come - I think they think this disease will contaminate them. When my daughter is sick it means I cannot even go out to the *shebeen* [bar]. (Doris, diary extract February 10th, 2004)

It was also revealed that livelihood and caring burdens may result in a range of emotions including irritability, loss of sensitivity, and withdrawal from the person requiring care. Because caring takes place within the private sphere of the home, carers became isolated with their concerns without access to help. That talking about their emotions with others, even within the household, was deemed unusual and even futile amongst those interviewed, further adds to the strains and isolation of caring.

HIV/AIDS-related stigma

Few people in the Caprivi are aware of their HIV status and those who are were reported to choose secrecy as a coping strategy if disclosure was considered to increase the stigma brought upon the household or was perceived as a threat to receiving care. However, while illness is often publicly represented as being caused by witchcraft, others may know or suspect HIV/AIDS. While the decreasing assistance provided to the main carer is due in part to the need for people to continue with livelihood activities, it is also due to the increasing trajectory of stigma attached to HIV/AIDS as the person's illness progresses (Alonzo & Reynolds, 1995) and their dependency prevents them from contributing to reciprocal support networks. Relatives and friends are crucial in providing ill people with an incentive to live positively and, if their HIV status is known, deal with their terminal status, thus a major source of support and motivation is removed when carers become fatigued and desensitised towards the ill person (Friedland et al., 1996). The following extracts

emphasise that stigma attached to HIV/AIDS can directly influence the well-being of the patient and carer.

> I stayed in another house when I was first sick in 2003. Those people I used to stay with [relatives] never cared about me because I had a long sickness and they would talk a lot and say that I had STDs and AIDS because I wasn't settled [staying in the village]. Then I went to my grandmother when I got very sick. My life felt so short. (Miriam, diary extract April 16th, 2004)

> It was so hard for a man like me to take care of a woman, but I never thought like that, I just knew that if I did not take care of my mum she could die and I would be alone. Some family members came to visit, but when we went outside they started saying that I was just wasting my time in taking care of her. When I asked them why they said she is affected with HIV/AIDS. I could tell that they were lying but I started crying. (Henry, diary undated 2004)

Miriam states that she did not receive adequate care from her relatives in town because of her long illness, and implies that her relatives would shame her, saying that through her immoral behaviour she had brought AIDS and STDs upon herself. Henry's comment emphasises how the support networks available to the carer may become less forthcoming if HIV/AIDS is known or suspected since caring is considered a "waste of time" when the patient will not recover (Ntozi, 1997; Seeley et al., 1993). Such feelings can result in accusations and anger directed against the patient and a subsequent breakdown in the provision of care.

> The carer [the mother] is not caring today as she says that Patricia is just pretending to be sick because others who have got ill since her have already recovered. She says that the reason she pretends to be sick is because she is lazy and does not want to work in her fields. The mother then went to her fields to do her work, leaving Patricia alone. (Patricia, diary extract February 19th, 2004 – recorded by HBC worker)

> The relationship between myself and my son [the carer] is not good because I refused to give him permission to visit his friends. Since then he is angry with me and my relatives left me without water. I don't know why, but when they are

happy they normally stay with me, and sometimes they just go to their fields
and say why don't I just get better. (Caroline, diary extract January 8th, 2004)

Patricia's case emphasises how the fatigue of caring duties over the past three years
have resulted in her mother accusing her of being "lazy", despite her obvious ill-
health preventing her from undertaking work. This demonstrates how a legitimate
'sick role' may be denied to people with HIV/AIDS as its unpredictable nature fails to
meet accepted understandings of illness (Finerman & Bennett, 1995; Weitz, 1989)
resulting in discrediting of, and frustration and hostility towards the ill person. In this
case, frustration is exacerbated by the fact that other people who have become ill
during this time appear to have recovered. The ambiguous status accorded to the
patient is also evident in Caroline's comment, stressing the fluctuating emotions of the
carer and demonstrating how carer fatigue can result in even basic care such as water
being denied to patients at times of household tension.

Patient well-being

Concern about their physical health was paramount amongst ill people keeping
diaries. However, with the exception of basic medicines purchased from local shops
or provided by HBC workers, it is necessary to seek treatment from further afield,
through the clinic, hospital or traditional healers. Considerable time and resources
must therefore be expended to secure treatment. While research in 'developed'
countries has found that people are able to negotiate and choose how they use
medication (cf. Wilton, 1999), such restrictions limit the possibilities for ill people to
reach treatment without assistance from family or friends. Diaries revealed that
household diagnosis and an inability to provide necessary resources meant that it was
not unusual for ill people to suffer extreme pain and debilitating symptoms both
before and between treatment, and that it was not uncommon for patients to go to
hospital only once critically ill. Patricia's diary emphasises the pain endured by
patients unable to gain access to treatment. At this point, Patricia had been
periodically ill for three years with HIV/AIDS-related symptoms, been diagnosed
with TB and prescribed a six month course of medication. However, because her
condition had failed to improve, and her relatives suspected witchcraft (requiring

'traditional' medicine), they were unwilling to spend further resources to take her back to the hospital.

March 3rd 2004

Today I'm a little bit better but I'm not feeling well in my head and I have fever and swollen feet. If I was the one who could make decisions, I would get people to find me medicines so that I can get treated and get better and start caring and living with my family again.

March 4th 2004

No-one helped me and I'm suffering from my body, feet and chest and also a headache. I wish I could get money easily which can take me to the hospital or admit me to the hospital until my treatment gets finished. Like this I won't be cured quickly because although sometimes when I have money I can go to the hospital, when I don't I can't go.

March 5th 2004

My eyes are swollen and dirty and painful like there is soil in them. My head is paining as if it is the lightning from the rain, and my face feels like it will fall down with fever. I'm worried that I have been sick without taking my medicines because I don't have anything and my parents are not here. My father passed away, so when my mother is not here I get things with difficulties and no-one helps me.

March 12th 2004

My opinion is that if it had been possible I could have stayed at the hospital until I got better, or that those who are caring for me come back from their fields. The family thinks that if it had been up to them I wouldn't have got sick because before I was living well and everything that I wanted I got easily because I was getting money. But now there is not money even to start a business. No-one helped me because they are still in their fields.

March 13th 2004

Today I'm feeling very painful toothache. It hurts like it wants to come out. I'm also feeling my shoulder as if something is moving in my spinal cord. My eye muscles feel as if they have been stabbed by a thorn. I'm worried that I don't have money to pay for the hospital and I don't have anyone who can take me there.

Source: Patricia's diary, 2004

As well as enduring continual pain, the diary demonstrates that although Patricia has been prescribed with TB treatment, she is unable to gain access to, and complete her course of medication, prolonging and exacerbating her illness and risking resistance to the treatment.

In cases, the health status of the sick person had begun to dominate their identity, a situation exacerbated by stigma and increasing isolation. With one exception, all patients recorded the manner in which their appearance had changed, and the upsetting impact this had upon themselves and others, particularly children. Several people suffered discriminatory comments regarding their appearance, resulting in a desire to withdraw socially and isolate themselves. It was also reported that in cases, such stigma prevents households accessing HBC assistance, a situation which became particularly evident when the patient had become seriously ill and the household did not want other people to see their condition. This not only prevents the carer from receiving assistance, but means assistance is denied to the patient.

Fulfilling social roles

In a situation in which motherhood is accorded significant status and value (Nashandi, 2002), the inability of women to fulfil their role as mothers and ensure the immediate and future well-being of their children emerged as a key concern. Five of the seven diary keepers had dependent children living within the household, several of whom were also ill with AIDS-related symptoms. During periods of illness, women expressed concerns regarding the health and care that their children were receiving, and their inability to provide adequately for them whilst they were ill. The comments recorded by Patricia were typical of diary keepers with young children.

March 1st 2004

Last night I fell down until Janet [12 year old sister] picked me up because I was feeling dizziness and cold in my bones...I am very worried about my child. He is sick and no-one is taking care of him, or can take him to the hospital because there is no-one here to help.

March 2nd 2004

Today I suffered a lot because my whole body is feeling pain. In this time my child is lying here feeling pain, and I am lying here without being able to help him. My thoughts today are not good because of my children who are very thin and there are no carers and no help because my mother who normally cares for us is away in her fields.

March 19th 2004

I'm worried about my children because since I got sick they are not receiving good care and they don't eat or wear clothes the way I want ….no-one is caring for them now while I am alive, so I am worried that if I die they will end up as beggars.

Source: Patricia's diary 2004

It was also common for women to worry over the future well-being of their children, particularly as no diary keepers had husbands to assume care for children in event of their death. Miriam described her frustration on hearing that her sister, upon whom she was depending for the future support of her child, drops out of school.

I was very angry when I heard that my young sister had left school. I felt pain because I didn't want these things to happen. My grandmother is getting older and she cannot afford things anymore. It would be better if my sister was [still] in school, so that she could help my daughter in years to come. I wish I had finished my secondary education and hadn't had a baby without a father. (Miriam, diary extract May 8th, 2004)

School policy in Namibia dictates that children are not allowed to miss school to care for ill relatives. However, while not as severe in the study sites as reported elsewhere

in Africa (cf. Robson, 2000; Rugalema, 1999), diaries reported that children did take time out of school to care. Several households reported that their children had performed badly or failed exams due to the emotional turmoil experienced when a household member suffered long-term illness, thus seriously jeopardising future livelihood prospects.

Fulfilling livelihood roles

People usually live with HIV/AIDS for a number of years, with significant periods of remission during which both the carer and ill person continue with livelihood activities. The necessity to maintain a livelihood and 'see for yourself' was stressed by Carina, since she cannot expect, or afford to pay anyone else to undertake activities for her.

> I feel that maybe I can do some work today because no-one else can work for me. I have to see for myself and do my own work. A person who eats cannot just sit, she has to work very hard. (Carina, diary extract March 14th, 2004)

Four of those keeping diaries had been ill for less than a year, and were to an extent able to continue with livelihood activities during periods of remission. At such times, well being was significantly raised as Clare explains.

> Today I lived very well because I prepared food for myself. I woke up well and went to collect firewood, wash dishes and do some things for life. I'm singing some church songs so that I may forget some of the things that disturb me…..I am very happy. I did not know I would reach [live until] this time. (Clare, diary extract March 5th, 2004)

The psychological well-being of patients was clearly influenced by the manner in which they were viewed by others. While they could feel neglected and isolated during times of dependency, their ability to contribute to the household brought an increased sense of well-being and optimism and decreased the level of stigma they perceived from others, enabling them to regain a level of self-control and reassert their role within the household. Miriam explains how she feels her ability to

participate and contribute to household activities has increased her social acceptance amongst others.

> I was dancing and I was happy as no-one was angry with me and my friends were happy like I was. After sweeping I told my friends I was ready to cook. They were happy to hear this because they never expected that I could cook….I was fine, there were no problems, and they were interested to be with me for long hours. (Miriam, diary extract May 19th, 2004)

Rather than being angry and frustrated with her as she felt people were while she was ill and dependent, Miriam comments that her friends are now willing to spend time with her. While this is due to her ability to contribute, it is also likely that the improvement in her health allayed the stigma associated with HIV/AIDS. The optimism associated with periods of improved health also enabled people to consider their long-term livelihood options. As Davies (1997) argues, the ability to project life plans to the future gives people a sense of ontological security, providing them with a belief that events can be influenced and controlled, and that their thoughts and actions have meaning and purpose, thus considerably enhancing psychological well-being. Most patients also expressed their feelings of gratefulness to their carers and their desire to repay relatives for the costs expended on treatment and care, implying that doing so would facilitate their re-integration into the household.

Dependency, isolation and rejection

Despite periods of optimism, the nature of AIDS-related illness invariably results in periods of sickness and dependency. Research has found that dependency upon others results in disempowerment and lowered self-esteem, decreasing well-being amongst ill people (Bharat & Aggleton, 1999; Dyck, 1995). Social pressures to 'see for yourself' or contribute to reciprocal support networks means this is particularly true in the Caprivi, and diaries revealed that patients were intensely aware of, and worried about, the time and resource costs their illness had upon the household. It was common for patients to compare their current position within the household to that prior to their illness. Patricia, who had formerly run a fish selling business and been able to contribute to the household, explains how she feels her role

has changed, and implies that she feels she is less valued within the household since she has been unable to contribute.

> I worry for my young brother. When I am sick he does not feel well, or feel like he is in the world because before I got sick I used to get things and I would give them to him. Even my mother is not seeing me the way she used to before I got ill. Now the money she gets is just spent on me for hospital and transport. (Patricia, diary extract March 8th, 2004)

During the course of the diaries, five patients commented that it would have been better if they had died rather than continuing to burden their relatives with the time and expense involved in care, and two referred to times they had considered suicide. Such anxieties and self-blame not only impact heavily upon the psychological well-being of the patient, they may also prevent the patient seeking treatment if they perceive that procuring medication will further disrupt the household. In Henry's household for example, the patient refused to let him take her to hospital, claiming that she did not want the household to be burdened with the additional costs of a coffin should she die there.

The long-term nature of HIV/AIDS can result in households becoming isolated through lack of time and resources to invest in maintaining support networks, and through stigma. While isolation is experienced by both carers and patients, bed-ridden patients are dependent upon others to visit them, while carers can choose to continue with livelihood and social activities. As Van der Geest (2002:16) states,

> Becoming dependent is a vicious circle. Those who don't go out gradually lose their social importance and become less and less interesting to visit. Being cut off from the information network that spreads through the community, they experience a gradual process of social death before they die in the physical sense.

The daily isolation and loneliness of patients was clearly evident in the diaries. One patient was left alone in the village for seven weeks with only her young siblings to help her and her sick infant children, while her mother worked away. The diary reported that the mother returned only once during this period to check-up on her,

despite the fact she was in extreme pain for much of this time. Isolation is also exacerbated by the layout of many settlements in the Caprivi, with accusations of witchcraft and subsequent family conflict resulting in wide dispersal of households. Rather than forming part of a busy and populous settlement, in which it is easy for people to drop in on a casual basis therefore, considerable effort may need to be expended to reach them.

Religion played an extremely important role for all patients, providing solace at times when people felt isolated from friends and relatives. However, interviews with church leaders in the region revealed a tendency to interpret illness as a punishment for immoral behaviour. Such beliefs inevitably impact upon the well-being of ill people, who may find themselves being judged by others for suspected wrong-doing or questioning their own behaviour in an attempt to understand their illness. Paradoxically, while this acceptance of self-blame can perpetuate the suffering of the ill person, it also provides a form of relief and optimism. By accepting they have done wrong, patients are able to actively attempt to rectify the situation through prayer, thus giving them hope that they will be forgiven and will recover. The following extract from Clare's diary demonstrates how such beliefs can promote an optimistic attitude that the illness is manageable.

> Today I'm sick I don't know what I must do. I feel lonely because of staying alone. But God as my witness, I know he is with me in all my deeds. So I will be better I know. I am so tired I can't even walk for a long distance. I will be praying to God so that I can get everything in an easy way. (Clare, diary extract March 10th, 2004)

While statements made during focus groups and by religious leaders asserted that people would continue to visit a person known, or suspected to have AIDS-related illness, patients explained that few people, including close relatives, had visited them whilst ill. None however, were willing to confront them over this issue, claiming that it was not their place to tell others what to do. Because of the pressures to 'see for yourself', it may also be the case that demonstrating a need for help from others is considered shameful.

Re-establishment of social networks

Household tensions arise due to the pressures and fatigue of long-term and stigmatised illness, fragmenting the support networks of the ill person and leaving them increasingly isolated as the illness progresses and their dependency increases. However, the stigma and tensions projected onto the ill person did not appear to be on-going following their death. Instead, the frustrations and ill-feeling that characterised the more difficult periods of the caring process were replaced with fond and affectionate memories of the deceased. With the possible exception of ill children, this research suggests that orphans play a key role not only in continuing the family line, but in restoring reciprocal support networks. Case study households in which orphans had been taken in explained that the orphans provided them with an emotional connection to the person who had died, thus helping cope with their loss. While their care imposed considerable economic burdens, the possibility of gaining access to maintenance or foster grants provided an important incentive to taking in orphans. The role of orphans in contributing to reciprocal support networks also emerged as a key factor in their 'adoption'.

> There are many benefits you can get from those children because they belong to your own children, your son's children. So they are like your own children and when they grow up they can get a job and can help to feed you and help you with things like ploughing. (Local chief, focus group, Sangwali)

Taking in of orphans is therefore considered a means to increase the labour and potential asset base available to the household, even if only in the future. While stigma and social fragmentation pervade much of the caring process, taking in orphans plays a key role in 'closing' the stigma and tension and facilitating the re-establishment of key social support networks.

Concluding remarks

An in-depth insight into intra-household experiences of long-term illness and caring has been demonstrated through the use of solicited diaries. While the sample size prevents generalisation of findings to a wider population, the findings indicate that HIV/AIDS can have considerable adverse impacts on households in the Caprivi.

Information recorded in the diaries demonstrates that while compassion and sympathy toward the ill person are evident in the early stages of illness, the long-term nature of HIV/AIDS makes caring a considerable burden upon household livelihood security and intra-household relations as the patient's condition deteriorates over time. The importance placed upon 'seeing for yourself' and contributing to reciprocal support networks mean that dependency upon others whilst ill was found to be a key factor influencing patient treatment, identity and subsequent well-being, a situation exacerbated by the terminal and stigmatised nature of AIDS.

A key part of HIV/AIDS mitigation lies in meeting growing care needs and provision of support for people living with HIV/AIDS. Increasing provision of anti-retroviral treatment across low and middle income countries will inevitably play a vital part in reducing episodes of illness and long-term care. However, stigma, gendered restrictions and resource accessibility mean that constraints to access and take-up of treatment will continue (Seeley, Grellier & Barnett, 2004). It is vital therefore, that locally appropriate initiatives are identified and developed in order to decrease the burdens of care and the subsequent stigma and neglect of ill people. As has been reported elsewhere in sub-Saharan Africa (cf. Chimwanza & Watkins, 2004; Katapa, 2004; de Guzman, 2001), the time and resource costs involved in taking an ill person to hospital, as well as overburdened health facilities and personnel (National Planning Commission, 2004) mean that caring in the Caprivi is likely to remain a home-based responsibility for the foreseeable future. Provision of more sustained and effective Home Based Care support is therefore vital, particularly for more vulnerable households with only limited capital assets. Such support should be strengthened through the development of counselling services which address the psychological and emotional impacts of AIDS and encourage testing, disclosure and support in order to delay and help manage the onset of AIDS-related illness. However, as Bharat and Aggleton (1999) argue, HBC projects are often based upon the premise that household resources are equitably distributed when in reality they are not. While HBC support undoubtedly plays a role in relieving the burdens of caring duties, it does little to challenge culturally embedded expectations that the duty of care lies only with women. Localised and participatory approaches are therefore necessary to promote the involvement of other household and community members in contributing to caring duties, actions which, in turn, have significant potential to decrease the burdens of care and alleviate subsequent intra-household tensions.

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[1] The first person to publicly admit their HIV positive status in the Caprivi Region did so as recently as December 2003.

[2] Overburdened health services in Namibia have been exacerbated by HIV/AIDS, with 50-70% of hospital admissions now thought to be AIDS-related (National Planning Commission, 2004). Combined with a lack of resources enabling many households to access care elsewhere, this has resulted in the duty of caring falling at household level. In response, Home Based Care groups have been established by NGOs and local health providers. Such groups visit households affected by illness to provide respite care, social and often spiritual support and occasionally medicines and food

[3] In one household, the carer left the village for several weeks - no information was recorded in her diary during this time.

[4] When possible, diary keepers were visited every two to three weeks. However, flooding meant that three households located in particularly remote villages were visited monthly. The HBC workers were able to continue visiting during this time because they were living in the same, or a nearby village.