

Abstract

Little attention has been given to understanding the emotional well-being of people living with HIV/AIDS in developing countries despite the fact that emotions may impact on people's sense of purpose and value, and ultimately their ability and resolve to hold livelihood and familial responsibilities together. Drawing upon research undertaken in the Caprivi Region of Namibia, this paper examines the use of solicited text and photo diaries in enabling insight into the emotional impacts of HIV/AIDS. The advantages and constraints of diary methods are examined, focusing on informant-directed research and the ethical considerations surrounding their use.

Keywords: Namibia, HIV/AIDS, emotions, well-being, solicited diaries, visual methods

Introduction

Undermining and even reversing the development efforts of recent decades, the HIV/AIDS pandemic constitutes one of the most profound and complex challenges facing poverty alleviation in 'developing' countries. Although research on HIV/AIDS has been dominated by a focus upon the illness as solely a clinical condition requiring medical treatment, a steadily increasing literature exists to examine the social and economic impacts of HIV/AIDS. In particular, focus has been placed upon rural livelihoods (Mathambo Mtika 2003; Rugalema 1999), microeconomic household impacts (Yamano and Jayne 2004; Russell 2004), changing demographics and dependency (Monasch and Boerma 2004; Williams and Tumwekwase 2001; Foster et

al. 1997), gender constraints (Gregson et al. 2004; Seeley et al. 2004) and macroeconomic impacts (Dixon et al. 2001). However, much of this work has focused on the objective and visible impacts of HIV/AIDS and with few notable exceptions (cf. Bolton and Wilk 2004; Baylies 2002) little attention has been given to understanding how affected individuals and communities themselves perceive and subsequently experience the epidemic. Research focusing on the more subtle impacts of HIV/AIDS on emotional well-being has been limited to people who are aware of, and able to openly discuss their HIV status. Much of this work has been conducted in ‘developed’ countries, amongst users of HIV/AIDS support groups (Wilton 1999; Friedland et al. 1996) and focus has been placed upon the process of diagnosis and the subsequent experience of ‘living with HIV/AIDS’.

While the emotional impacts of HIV/AIDS such as grief, sorrow, anger and shame may impact on people’s sense of purpose and value and ultimately their ability and resolve to hold their livelihoods and familial responsibilities together (Seeley 2001), little attention has been given to understanding the emotional well-being of people living with HIV/AIDS in developing countries. This is due partly to the widespread existence of HIV/AIDS-related stigma which discourages HIV testing and fuels the denial or withdrawal and isolation of people living with HIV/AIDS. However, it is also reported to result from a general reluctance or perceived inability amongst those working in ‘development’ to confront such emotional issues (Seeley and Pringle 2001) as well as a prevailing tendency for research in health geographies to be confined to select areas of the ‘developed’ world (Kearns and Moon 2002). Drawing upon fieldwork undertaken in the Caprivi Region of Namibia, this paper explores how the use of solicited text and visual diaries elicited detailed insight into the personal experiences and emotions of a sample of people living with long-term

and stigmatised illness. The ethical implications of the diary methods are then examined.

Health and Emotions

In his review of the medical geography literature, Kearns (1996) called for a change of direction which recognised not only the distribution and diffusion of the HIV virus, but also the emotional experiences and well-being of people living with HIV/AIDS. In response, geographies of health and illness have been at the forefront in acknowledging that physical and emotional experiences are intrinsically linked (Basu 2006; Davidson and Milligan 2004; Kearns and Moon 2002), and must be seen within the context of the changing embodied relations, discourses and socio-cultural environments in which they are located (Thien 2005; Bennett 2004). Attempting to recast “subjects of research as *persons* rather than as *patients*” (Kearns 1995, 252), increasing focus has been placed on the emotional and subjective perceptions of people themselves, with growing acknowledgement that well-being is largely determined by a person’s capability to “choose a life one has reason to value” (Sen 1999, 74). Ill-health and ill-being may therefore encompass not only the physical impacts of the ‘disease’ or ‘affliction’, but a range of more emotional factors such as exclusion, insecurity, powerlessness, self-respect and personal beliefs (Dean 2003).

More recently, an emerging interest in emotional geographies has brought increasing recognition that social relations are lived and experienced through emotions (Bennett 2004; Zautra et al. 2004; Anderson and Smith 2001; Laurier and Parr 2000; Widdowfield 2000). Rather than being irrational, disruptive and overly subjective, it is argued that emotions are intrinsically bound up with wider structures and processes (Basu 2006; Thien 2005; Bondi 2005) and thus affect the changing

ways we perceive and react to the people, places and environment around us (Milligan 2005; Kim-Prieto et al. 2005). As Anderson and Smith (2001, 7) state, “At particular times and in particular places, there are moments where lives are so explicitly lived through pain, bereavement, elation, anger, love and so on that the power of emotional relations cannot be ignored.” Consideration of emotions is therefore central in any attempt to understand how social relations mediate the ways in which “lives are lived and societies made” (ibid), and the dynamic sense of whom and what we are.

While much of the literature on emotional geographies has focused upon the emotional processes involved in *doing* research (cf. Widdowfield 2001; Hubbard et al. 2001; Meth with Malaza 2003), Bennett (2004) supports a body of literature in the wider social sciences (e.g. Katz 1999, Barbalet 2002) in stressing the importance of considering the emotions of the ‘researched’ in enabling contextual understanding of the ‘rules’ and structures that help shape emotional behaviour and well-being. However, eliciting such emotive and often sensitive information raises a number of methodological and ethical issues, particularly when research is carried out in other cultural contexts in which open displays of emotion may be relatively restricted or differently defined.

Using solicited diaries in the Caprivi Region

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 are involved in an array of activities to meet food and cash requirements. The Caprivi’s status as one of the least developed regions in Namibia (Mendelsohn et al. 2002) is primarily caused by decreasing life

expectancy, caused (and exacerbated) by HIV prevalence rates of 43% amongst the adult population (MOHSS 2004).

Using a range of qualitative methods, the wider research programme aimed to examine the impacts of HIV/AIDS on livelihoods, vulnerability and support networks in three rural villages in the Caprivi Region. A livelihoods survey with 100 households and participatory methods were used to initiate discussions of the perceived impacts of HIV/AIDS. Semi-structured repeat interviews with 18 case study households enabled investigation into household composition and transfers, coping strategies, belief systems and the perceived impacts of illness and death. In addition, 12 focus groups provided further insight into customs and norms and local understandings of HIV/AIDS. These methods provided in-depth understanding of the socio-cultural, economic and environmental context of the study sites, and the perceived impacts of HIV and AIDS on livelihoods, vulnerability and support networks. However, it became clear that households in which a person was currently ill with AIDS-related symptoms were under-represented in the research and that open discussion of HIV/AIDS was only possible in a generalised, non-personal context. The reluctance of such households to participate was due largely to their lack of available time between caring duties and livelihood activities. One way to ensure that the research gave voice to people experiencing illness was through the use of solicited text and photo diaries.

Although often overlooked as a research method, solicited diaries have proved important in research on health and behaviour (Coxon 1998; Elliott 1997). However, as Crang (2003, 493) argues, qualitative methods that are “often derided for being somehow soft and ‘touchy-feely’ have in fact been rather limited in touching and feeling” and the use of diaries has tended to focus primarily on the recording of daily

activities and bodily practices. With few notable exceptions (cf. Meth 2003), little attention has been given to eliciting the personal emotions which influence, and are influenced by, the experiences and actions of those recording the diaries. In this research, solicited text and photo diaries were used to gain in-depth insight into the emotions of people living with AIDS-related illness. Used in conjunction with the methods applied in the wider research study, this enabled deepened understanding of the context in which such emotions were felt, and the ways in which emotions were intimately bound up with personal relations, identity and well-being.

Before discussing the commissioning of the diaries, it is important to recognise the cultural context in which the diaries were undertaken. Socio-cultural norms and notions play a key role in influencing displays of emotion (Tan et al. 2005) and in this research, there was a clear distinction between emotions displayed in public and private spaces. Public displays of emotion were restricted, with funerals providing one of the few public arenas in which emotions such as grief and sorrow were openly displayed, and particularly amongst women, expected.¹ When asked about emotional support networks however, people frequently commented that they did not tend to share their negative emotions with others. The main reasons given for this was that it would not be of any help to do so, that burdening someone else with one's emotions was inappropriate and shameful, and that divulging one's feelings may result in hurtful gossip. While talking about illness in a general context was not tabooed, the stigma surrounding HIV/AIDS meant that openly discussing people's personal experiences of illness risked upsetting, offending and stigmatising the ill person. A major advantage of the solicited diaries was that they enabled people to express their thoughts and emotions in writing, thus avoiding the potential upset and harm that may have arisen through more conventional interviewing methods.

To commission the diaries, it was necessary to work through Home Based Care (HBC) workers in the study sites 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. It was made clear that diary keeping was voluntary, but all of those approached agreed to participate. 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.

Diaries were kept by seven people living with AIDS-related illness 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. 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. Diaries were recorded in the preferred language of each recorder, and those not written in English were translated by my interpreter.² Although some consider the process of paying research informants as a reassertion of power relations (cf. Ansell 2001), I agree with McDowell (2001) who argues that it is appropriate to provide an incentive, or in some way recompense those involved in research, and believe that not doing so can also be exploitative and reinforce power relations over the 'researched'. After discussions with my translator and HBC workers, it was decided that the most appropriate payment would be in the form of a

small but significant sum of money. Thus, those keeping diaries and the HBC workers ‘supervising’ the process were each paid N\$100 (approximately £10) once the diaries had been collected.

Although cultural norms and lack of resources meant that self-expression through diary keeping was not common in the Caprivi Region, popular media (in particular radio and newspapers) meant that all informants had heard of, and understood the rationale of diary keeping. However, rather than being private documents, diaries solicited specifically for research purposes “are written with a particular reader and their agenda in mind” (Elliot, 1997, 9), a factor which may potentially bias the information recorded. 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 living with illness. However, it was made clear that they were free to write what they wished, and that the N\$100 payment was not dependent on the type of information recorded.

In combination with the written diaries, the research also drew upon autophotography to gain a deeper understanding of the emotions and experiences of people living with long-term illness. While interviewing methods can create and reinforce the dominant frames within which knowledge is realised, autophotography draws upon people’s visual imaginations (Latham 2003), enabling it to be an inclusive and empowering research method which documents knowledge from the perceptual orientation of the informant (Dodman 2003; Harper 2002; Markwell 2000). While autophotography does not usually provide a daily reflexive account in the same way as written diaries, it is argued that photographs are “deeply embedded and contextualised by the personal lives of the producers” (Rohde 2001, 189), and enable access to places usually inaccessible to a researcher (Young and Barrett 2001). In this

research, each diary keeper was given a disposal camera to record people, objects or places that had been important or influential in their lives since becoming ill, in both a positive and negative sense. To avoid misrepresentation and decontextualisation of the pictures, each person was asked to record the context in which each photograph was taken. While some people used up their film within a few days, others took their pictures over a period of several weeks, taking time to think about and decide upon which experiences they wanted to represent visually. Respondents took photographs which reflected their current emotions and experiences, as well as pictures of people or objects that had had a significant or long lasting impact upon their lives, thus adding further depth to the information recorded in the diaries. As has been recorded elsewhere (Latham 2003; Young and Barrett 2001) autophotography used in combination with other methods also enables triangulation of data, in this case with the information recorded in the diaries and the wider research project.

Recording emotions

Kearns and Moon (2002) stress the need to move beyond snapshot studies to consider the dynamic nature of the health and illness process. The time-consuming nature of the case study interviews in the wider research meant that interviews were conducted with HIV/AIDS afflicted households in which the ill person had already died. The information recorded was often based upon events from several years past, which although useful in providing a more reflective interpretation of the impact of HIV/AIDS, presented a relatively static interpretation of the illness and caring process, and reflected the emotions of the interviewee only on the day in which the interview took place. In contrast, while some diary keepers provided a retrospective account of some of their most memorable experiences, others wrote on most days,

enabling the illness ‘process’ and the fluctuating emotions of the diarist to be followed over time as they were experienced.

Fear and confusion

The intense stigma associated with HIV/AIDS meant that it was unclear how many of the diary keepers were aware of their HIV status. Given the low level of HIV testing within the region, it is likely that few people actually knew their HIV status, and that those who did felt unable to disclose this to other household members. Studies in developed countries have found that awareness of HIV status has enabled people to come to terms with their positive diagnosis, ensure they are knowledgeable about the potential implications of the illness and actively plan their lives around this (Ezzy 2000; Wilton 1999; Friedland and Bennett 1995). However, this was clearly not the case amongst those keeping diaries in the Caprivi, and it was evident that fear and confusion over the long term and variable nature of the illness dominated the emotions of ill people. At several points in her diary for example, Gertrude recorded her worries and confusion over the increasing severity of her illness.

I can see that these sores will cause my death because they don't get any better. When they finish they just start to grow again. Many people are laughing at me that its HIV/AIDS otherwise I'd have been cured. I've never seen these sores before in my life – maybe someone has witched my body and that's why they don't go away.
(Gertrude, diary extract, undated)

Although it was possible to obtain basic medicines locally, it was necessary to travel further afield and to pay fees to secure prescribed medication. Ill people were

therefore dependent upon the help of others to gain access to treatment, which, as Claire states, led to considerable anxiety when help was not forthcoming.

My tablets have finished and I don't know where I can get money to buy more so I think this will be the end of my life....I asked my father but he said I had to wait. I am so confused I could easily kill myself. (Claire, diary extract, April 22nd 2004)

While the changing relationship between the carer and the ill person has been addressed elsewhere (Thomas forthcoming), it is important to note that the resource constraints facing the household, as well as the burden and fatigue of long term care meant that the level of support provided to the ill person varied, leaving them emotionally distressed when care was less forthcoming than they wished. Several people recorded instances when they had been left alone in the household, sometimes without access to basic resources such as water. Photographs taken by diary keepers recorded the important role played by children in providing a non-judgmental and supportive role during times when other household members were absent or appeared unwilling to help.

Frustration and loss of purpose

It is recognised that solicited diaries can provide insight into the taken for granted assumptions that shape everyday actions and meanings (McGregor 2006). While the ability to be independent and 'see for yourself' i.e. be self-sufficient, had emerged during the wider research study, the relevance of these issues in influencing identity and self respect was brought to the fore within the diaries. The nature of AIDS-related illness meant that over time, the caring and illness process extended over significant

periods, often several years, during which the carer and the ill person were unable to maintain full involvement in livelihood activities. All the ill people keeping diaries expressed feelings of guilt and remorse over their inability to fulfil livelihood responsibilities and the knowledge that the cost of resources diverted to caring and treatment was threatening household livelihood security. Deeply aware of the resource costs of their illness, several, such as Patricia, expressed their desires to repay their relatives once they had recovered for the costs they had incurred.

My parents lost a cow and \$1000 for the traditional healers, hospital, transport and food. My worry is how I will get a job so that I can pay back what they have lost.
(Patricia, diary extract, May 1st, 2004)

In cases, the pressure to avoid becoming a burden to others led to ill people denying their needs and depriving themselves of treatment. As Henry explains, his mother refused to go to hospital for treatment, fearing that the household would be encumbered with the cost of a coffin should she die there.

My mother said that it's better for her to die in the village rather than at the hospital because no-one will be able to give us money to buy a coffin. I had to trick her to go to the hospital – when she realised she was there she was so angry with me. (Henry, diary extract, undated)

The loss of purpose felt by those unable to carry out livelihood duties, was exacerbated by the difficulties they faced in fulfilling familial responsibilities. During

periods of illness, diary keepers expressed concerns regarding the care that their children were receiving, and their inability to provide adequately for them whilst they were ill. Patricia and Gertrude's diaries showed clearly their concern over the current and future security and well-being of their children.

My thoughts today are that when I'm sick my children worry me because care is lacking and they are not eating and wearing [clothes] the way I want them to be as a mother.....they feel lonely because they miss me as I'm the only one they trust in their lives. I didn't see any help because my carer is still not around. (Patricia, diary extract, March 9th 2004)

Now I think when I will die where will my children remain and what are they going to eat and who will pay for them in school, so they will drop out from school when I will die. This is the most serious thing I think about when I'm very sick. (Gertrude, diary extract undated)

Optimism and sense of purpose

While many of the emotions expressed through the diaries were understandably negative, the illness experience was a dynamic process, with significant periods of enhanced well-being recorded during periods of illness remission. While this was due in part to people's optimism that they were recovering from the illness, their ability to be independent and fulfill familial and livelihood roles was of paramount importance in enhancing their sense of value and purpose. Miriam for example, recorded her happiness at being able to continue her livelihood activities, while the photographs

illustrated in Plate 1 demonstrate the importance attached to ‘seeing for yourself’ and achieving at least a level of independence.

I was so excited when I woke up – I washed my sandals on my own and no-one helped me. I asked my brother to take a picture while I was doing this as I was so happy not to feel any pain. (Miriam, diary extract, May 10th 2004)

Plate 1: Photographs taken by people living with long-term illness to demonstrate the importance of ‘seeing for yourself’

Ethics and emotions

The use of solicited diaries for undertaking emotional research clearly raises a number of ethical issues. Of paramount significance is that the very process of diary keeping undoubtedly played a role in creating some of the emotions recorded. Whilst conducting research that is potentially upsetting disrupts the over-riding and usually unquestioned ethical objective of ‘avoiding harm’, it also raises important questions regarding how harm is defined and by who, what level of harm is deemed (un)acceptable and how the costs to individuals are weighed up against the collective needs or potential benefits of raising awareness of the particular group in question (Meth with Malaza 2003; Robson 2001). This also links into debates concerning confidentiality and exploitation, and these issues will be examined now.

Whilst the diaries were translated in the field, the delay between the writing and translation of the information meant that it was not possible to follow up issues raised at the exact time that the diaries and associated emotions were recorded. Any

emotional issues discussed when clarifying diary entries were therefore retrospective to the emotions actually experienced. While my translator and I were able to listen sympathetically on occasions when people did choose to discuss their feelings and experiences, and inform people about the new anti-retroviral treatment scheme starting in the region, not being a trained counsellor meant that it was not appropriate to try and offer direct counselling support to diary keepers. On reflection, it is possible that more support and counselling could have been sought from professionally trained personnel, although this in turn would have raised issues regarding confidentiality and anonymity, and, given the limited public displays of emotion in the Caprivi, would possibly have been considered culturally inappropriate.

As Cloke et al. (2000) state, the process of research impacts not just upon the ‘researched’, but also indirectly, upon those who belong to their social worlds. Because diaries were recorded in the private sphere of the household, it is not possible to know how their recording impacted upon intra-household relations. Tensions between ‘patient’ and carer were recorded in several diaries (cf. Thomas 2006), and it is possible that these issues were exacerbated by the diary keeping process, although this was never stated to be the case. Separate books and pens were provided for each diarist, thus limiting the opportunity for potentially upsetting statements to be seen by each person. Given the nature of the household compounds, it would, however, have been difficult for diary keepers to keep books hidden. One solution to this would have been to store diaries with a neutral party such as a HBC worker, although this again would have raised issues of confidentiality and safe storage, as well as prevented the diary keeper from recording their experiences and emotions as they happened.

It is also not possible to rule out the possibility that participating in the diary keeping increased stigma directed against the ill person. In an attempt to avoid this, it

was ensured that a wide range of households, a number of which had not been directly affected by HIV/AIDS, participated in the wider research programme. However, I was acutely aware of the potential sensitivities of the diary keeping, and asked diary keepers and HBC workers to inform me as soon as possible if they felt that participation in the research was impacting adversely upon them. During informal discussions with participants, it was in fact found that as well as relieving boredom, the diary keeping process was found by some to be therapeutic and that involvement in the research had made them feel that their opinions were valid. On reflection, a greater understanding of what role, if any, the diary keeping played in enabling diarists to unburden any feelings of guilt, regret or sadness that they had been unable to talk about with relatives or friends would also have been interesting, and would have added greater depth to understanding the process of diary keeping.

One key advantage of the diaries was that they gave authorial control to the diarist, enabling them to set their own agenda and reveal information as they wished. While it is recognised that information could also be concealed (a problem faced equally through interview methods), the diaries gave informants time to think through, define and prioritise the issues and experiences that they felt were most important to them and to raise them as and when they wished. 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.

The time and emotional costs of the diary keeping raises questions about how, if at all, it was best to provide short and long term support to participants. All of the households concerned were engaged in subsistence-based livelihoods, and time spent

writing the diaries diverted them away from these activities. The cash incentive was therefore provided to recompense them for their time. Participants were also given copies of the photographs they had taken, which for many was considered important, especially when they had taken pictures of family and friends. There were also times when I helped out by giving people lifts to the clinic and occasionally providing food. Whilst the ethics of these actions may be considered contentious, I was clearly in a position in which I could provide such help and I would argue that the ethics of doing nothing in such a situation are morally dubious.

Another form of support identified as a result of the diaries concerned the role of the HBC workers. HBC workers reported that because they were involved in monitoring the diaries, they visited households and helped them with respite care and support more frequently than would have otherwise been the case. They also reported that they were more aware of, and thus able to respond more fully to the needs of the ill person and the carer.

Conclusion

This paper has argued that when used in conjunction with other qualitative methods, solicited text and photo diaries can elicit in-depth and sensitive information on the emotional impacts of HIV/AIDS. Whilst the findings are in no way intended to be generalised to a wider population, they clearly indicate that living with long-term and stigmatised illness can play a central role in shaping people's identity, self-worth and well-being. From a policy perspective, such findings clearly indicate the need for the development of locally appropriate counselling services which address the emotional and psychological impacts of living with chronic illness, as well as encourage HIV testing, disclosure and support to reduce stigma and delay the onset of AIDS-related

illness. Given the time and resource costs of accessing formal health facilities, HBC workers are well placed to play a central role in such a development.

The use of solicited text and photo diaries facilitated the collection of in-depth information on people's emotional experiences, and enabled a level of informant-directed research. However, whether these methods are emotionally harmful remains unclear and the ethical implications of their use must be fully considered in light of the context in which they are to be used.

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¹ Prior to the coffin being brought into the funeral ceremony, female relatives would gather in the courtyard of the deceased to show collective displays of grief through loud wailing and screaming.

² There are six major languages in use in the Caprivi Region. Because my translator spoke all of the languages of the area fluently, it was possible for diarists to write (and speak) in their preferred language during the research. My translator was a trained Home Based Care Worker from the region who I recruited with the assistance of the local hospital.