Exploring perceptions and emotional burdens of HIV/AIDS health care workers

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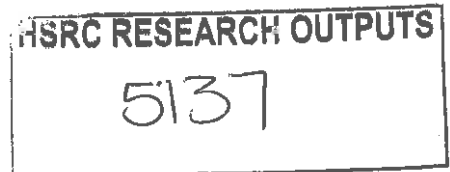
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Abstract

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The scope of the HIV/AIDS epidemic in South Africa poses challenges for an already overburdened health care system. In this study, we explore the perceptions and emotional experiences of HIV/AIDS health care workers in a rural area of the Limpopo province. Ethnographic methods, including a focus group interview, field notes, informal conversations and official health information and statistics, were used. Eight health care workers participated in the FGD, viz. two female home-based carers, one male home-based carer, four male lay counsellors and one female professional nurse participated in the focus group interview. The health care workers reported experiencing love for their job, personal rewards and growth. Accounts of negative emotional experiences were however dominant. The health care workers told of challenges related to a lack of resources, increased health provision demands, lack of training and support, limited government involvement, and a constant emotional overload. They felt emotionally exhausted; with limited possibilities of professional accomplishment and recognition; and they felt that the interactions with patients were demanding and sometimes negative. The described experiences were compatible with symptoms of burnout. We argue that the pronounced need for debriefing and emotional support should be met with systematic guidance and support measures that could alleviate or prevent symptoms of burnout and enable a healthy workforce.

Key words: Burnout, client-centred approach, debriefing, emotional support, patient-caregiver relations

Introduction

As the number of South Africans infected with HIV is approaching 6 million (Department of Health, 2006; UNAIDS, 2006), the burden on the health care system increases concurrently. A national survey found that within the public and private health care system, 28 % of patients seeking health care services were HIV positive. Almost half of the patients in public hospitals, and an alarming 15, 7 % of the health care workers were HIV positive (Shisana, Hall, Maluleke et al., 2002).

It took the South African government long to admit the existence of and to step up to the fight against HIV/AIDS. It has been argued that there is still an alarming lack of government leadership and support in South Africa in relation to the epidemic (Cameroon, 2005; Lewis, 2006). In 2003, the World Health Organization launched its "3 by 5" strategy, stating that within 2005, 3 million people should be enrolled on antiretroviral therapy. So far, the roll-out in South Africa has been slow and riddled by problems. UNAIDS (2006) has estimated that only 10-15 % of the South Africans in need of antiretrovirals received them by the end of 2005. The Limpopo province, where this study was undertaken, was the last to roll-out. Only 63 patients in selected clinics and hospitals in Limpopo province were receiving antiretroviral treatment by September 2004 (Department of Health, 2004).

For most HIV positive patients there is still limited access to care, support and treatment. The public health services, which are the only options for the majority of people infected, are generally overburdened and medical services and treatment are often inadequate (Boulle, Blecher & Burn, 2000). Many patients are discharged from hospitals without access to any organised care and support (Steinberg, Johnson, Schierhout & Ndegwa, 2002). Kober and van Damme (2004) argue that the lack of a comprehensive human resources strategy is a major challenge facing the African public health system. There is a shortage of qualified health workers, especially in the rural areas, wages are low, and the workloads are heavy (Benatar, 2004). In the Limpopo province, the vacancy rate for health workers stood at 36 % in 2005 (Limpopo Department of Health and Social Development, 2006).

To alleviate the burden faced by professional health workers, most health centres, clinics and hospitals now have lay counsellors employed as part of their health care staff. They assist in the provision of Voluntary Counselling and Testing (VCT), which is a cornerstone of HIV related health services. Counselling includes provision of emotional support, information, education and guidance, and counsellors use both client-centred and more directive, health-advising techniques. Lay counsellors are usually trained by non-governmental organizations (NGOs) and work alongside professional nurse counsellors, doctors and other health care personnel (Rohleder & Swartz, 2005). The introduction of lay counsellors has led to improved service for HIV positive individuals. The formal health care system also works in partnership with community-based organizations (CBOs) and volunteers. Most notably, home-based care has become an important service for patients that are ill, bed-ridden or dying from AIDS (Barnett & Whiteside, 2002).

Stress and burnout in health care workers

According to Payne (1999) stress can be understood as a process that occurs when people find themselves unable to deal adequately with the stressors facing them. Among stressors mentioned in the literature on HIV/AIDS care are systemic challenges such as lack of resources, support and training (Ross, Greenfield & Bennett, 1999); heavy patient flow; heavy and unpredictable workload (Grinstead, Van der Straten & The Voluntary HV-1 Counselling and Testing Efficacy Study Group, 2000); role conflict or ambiguity (Murphy, 1999); the physical symptoms and inevitable death of patients with HIV/AIDS (Akintola, 2006); uncertainty (Held & Brann, 2007); over-involvement with HIV positive patients (Akintola, 2006); and secrecy and fear of disclosure among HIV positive people (UNAIDS, 2000).

Working with HIV/AIDS care places considerable emotional demands on caregivers (Orner, 2006). Primary health care workers have reported feelings of fear and helplessness in providing care for HIV positive patients (Smit, 2005). Emotional exhaustion and fatigue are common in health workers who often work under great pressure with a stigmatized disease, meeting death and misery on a daily basis, without sufficient compensation or encouragement. Moreover, these health care

workers are often thrown in the deep end without receiving adequate, on-going training and supervision. They are often expected to deal with clients' complex and difficult emotional problems (Richards & Pennymon, 2005 in Madu and Govender). Thus, demoralisation and demotivation has been reported among health care workers (Schneider, Blaauw, Gilson, Chabikuli & Goudge, 2006). Shisana et al. (2002) found that a third of South African health workers reported low morale due to factors such as stressful working conditions, heavy patient workload, staff shortages and low salaries. Mackintosh and Tibandebage (2000) described how nurses felt overloaded and abandoned by doctors formally responsible for patient care, and how this could lead to a 'culture of abuse' directed at patients, sometimes resulting in aggression, disrespect, and insensitive behaviour from health workers towards HIV positive patients (Jewkes, Abrahams & Mvo, 1998; Ehlers, 2006). In the light of the exceeding demands of HIV/AIDS care, health care workers might not be able to successfully cope or find meaning and benefit in their work situation. They stand the risk of burnout.

Burnout is, according to Maslach (1993), characterized by emotional exhaustion, depersonalisation and a sense of reduced personal accomplishment, accompanied by a decrease in motivation and an increase of dysfunctional attitudes and behaviours. Emotional exhaustion occurs when a person becomes too emotionally involved and stretches him or herself too far to meet work related demands. Depersonalisation is characterised by negative, detached, cynical or even inhumane attitudes and behaviours towards the recipients of services. Reduced personal accomplishment involves a negative perception of one's work that may lead to feelings of inadequacy and failure. Burnout is a result of chronic occupational stress in "normal" individuals, and might occur for a variety of reasons. These include job-related stressors (e.g. time pressure, role ambiguity, lack of support), personality and demographic factors (e.g. poor self-esteem, non-confronting coping style, age, own health), as well as system or organizational issues (e.g. absenteeism, job turnover, lack of infrastructure) (Ross & Seeger, 1988; Schaufeli & Enzmann, 1998).

Previous research on HIV/AIDS care and support has primarily focused on HIV/AIDS patients. There is limited knowledge about health care workers' perceptions and emotional experiences of providing HIV/AIDS related care and support (Carlisle, 2000; Benevides-Pereira & Alves, 2007; Held & Brann, 2007). In

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this article we report on primary health care workers' perceptions and emotional experiences in relation to the challenges and stressors they encounter in their daily work situation. Their emotional experiences are discussed in light of the theory of burnout. There is an urgent need for supportive efforts to enable health care workers to perform their tasks without the risk of developing a burnout syndrome. We conclude by suggesting ways to care for the carers to alleviate emotional burden and prevent potential burnout. The data was collected in a rural impoverished area of the Limpopo province of South Africa in October 2004, two months after the provincial introduction of antiretroviral treatment.

Background

The material presented in this article is part of a longitudinal project (2003 – 2005) aimed at setting up a holistic care and support system for HIV positive people in a rural, impoverished area of the Limpopo Province in South Africa. The support system was based on a mapping of experiences, coping and accessibility and availability of care and social support through interviews, questionnaires and focus groups involving 250 HIV positive men and women; 22 couples; and health care workers. The project was evaluated in August 2005 (Dageid & Duckert, submitted).

The local health care area where this study was conducted encompassed 19 local clinics and one hospital. All of these public health care facilities were offering VCT services. Antiretroviral treatment had been provided at the hospital since August 2004. Clinic staff typically consisted of nurse(s), nurse assistants and one or more HIV/AIDS counselors, dependent on clinic size and location. The clinics made referrals to the local hospital for secondary and tertiary health services. In 2003, the hospital hosted its own HIV/AIDS clinic once a week. Patients were able to see an HIV counselor, a nurse, the doctor and social worker in parallel sessions.

In addition to the formal health care services, several community based organizations and groups provided HIV/AIDS related services in the area. These included home based care, support groups, child and orphans drop-in centers, youth clubs, faith based organizations and traditional healers' forums. At a regional level, governmental and bigger non-governmental organizations would offer services. HIV

positive patients would be referred to or encouraged to seek the services offered by such organizations or groups based on their needs.

Method

Ethical approval was obtained from the Limpopo Department of Health & Welfare and The National Committees for Research Ethics in Norway (REK). The ethical standards of research were adhered to. The study was based on the use of ethnographic methods; including a focus group with health care workers, field notes, informal conversations and official health information and statistics.

Procedure and participants

Informal conversations with health care workers had taken place from the start of the project in March 2003 until the end in August 2005. The first and second author had spoken with home-based carers, lay counselors, nurses, doctors, administrative and management staff, NGOs and CBOs, local leaders, governmental health officials and other HIV/AIDS researchers. Keeping this information in mind, we also conducted a more formal discussion with health care workers in order to obtain more systematic information about their perceptions and experiences of their work situation.

Participants for the focus group discussion were recruited through purposeful sampling (Patton, 2002). In October 2004, a letter of invitation to participate in the focus group discussion was distributed to the doctor(s), counseling nurses, lay counselors and home based care workers connected to the HIV clinic at the hospital, and to the lay counselors at the five primary health care clinics in close proximity to the hospital. The reason for choosing these individuals was that they would be most likely to have cared for the HIV positive people that were part of the overall longitudinal project. The choice of a focus group session was preferred as it -in the context of an overburdened health system – saved time for the participants. This was also an opportunity for participants to share their experiences; highlighting issues about their roles in the public health care system. Also, focus groups are beneficial

for identification of major themes as well as for providing checks and balances on the individual participant's views (Krueger & Casey, 2000).

Eight health workers participated in the focus group discussion. The group consisted of two female home-based carers, one male home-based carer, four male lay counsellors from different clinics and one female professional nurse from the hospital. They were in their late twenties to early forties. One of the lay counsellors was HIV positive and was open about his status. (After the completion of the focus group interview, one of the other health workers told the first author that she too was HIV positive. She had not wanted to reveal her status in the group). Reimbursement consisted of a light meal/lunch and money for transport. The location was a quiet office building close to the hospital.

The discussion focused on two main themes; 1) availability, accessibility and utilisation of services based on the clients' needs as well as health workers' perceptions of client needs; and 2) the health workers' own work situation, including professional position and training, quality and effectiveness of service provision, cooperation within the health sector, challenges the health workers faced in providing HIV/AIDS related care, and suggestions for improvements of their own work situation and that of the health care system. The focus group discussion was conducted in English and lasted for almost three hours. The first author acted as a facilitator and moderator, leading the group discussion through the two themes, and followed up interesting topics as they emerged.

The first and second author kept field notes covering observations, informal conversations and reflections in meetings with individual health care workers and other stakeholders, HIV positive patients, and the health care system as a whole. We also made an effort to keep updated on the policies, programs and activities in our local area of research.

Data analysis

We chose a pragmatic triangulation approach when analyzing our data. The focus group discussion was audio taped and transcribed verbatim. The transcripts were then analysed by means of thematic analyses, following the guidelines presented in Patton (2002). A preliminary list of categories was developed from the themes that guided the focus group session. The first and second researcher individually read

through the transcripts several times. We examined the manuscript word by word, line by line and compared and combined sentences and paragraphs to identify primary patterns. Categories and themes emerged through this process, and the original list of themes was revised. The emergent themes were then discussed and refined, and compared and contrasted to the information from our field notes, statistics and public health information, as well as the informal conversations. Finally, our findings were compared to literature and other research findings, and suggestions for improvements were made. The computer software N-VIVO was utilized during the process of analysis. The results will focus on the health care workers' emotional experiences related to their work situation. Verbatim quotes illustrate the findings.

Results

In general, the eight health workers reported both positive and negative emotional experiences in their daily work. While acknowledging the positive aspects of their work, their accounts focused strongly on the emotional challenges related to working within the HIV/AIDS health care services.

Positive emotional experiences

Love for the job

All the eight health care workers experienced their jobs as meaningful and important. They typically said they had endured the many difficulties related to working with HIV/AIDS because of dedication and *"love for the job"*. Meaningful aspects of the job included helping fellow community members to cope with their status, to help them disclose and overcome stigma, and to assist them in 'positive living'. All the health care workers acknowledged the enormous need for support among HIV positive people, and most of them believed they could make a difference. Loving the job was also a way of loving oneself, as observed by this HIV positive lay counsellor:

If we can keep that in our heart saying that 'let's love our jobs' some day you will see, even the stigma and discrimination around people living with HIV/AIDS- it will go away because everybody will be understanding, saying that 'Ok, we are treated in the equal way and everything is done like that'.　　　　　　　　　　　　　　　*Lay counsellor 3*

Personal reward and growth

All the health care workers reported a sense of responsibility and accountability towards the community and towards people living with HIV/AIDS. They stated that they were working in the HIV/AIDS sector because they wanted to assist their communities in a professional way. One of the lay counsellors was also a professional teacher, but said he had chosen to work as a lay counsellor because he would be able to *"reach more people"* with the messages of HIV/AIDS. Another lay counsellor reported that he was *"empowering people"* through his work. HIV positive people are often portrayed as 'victims' or 'sufferers'. Yet some health workers drew attention to the resourcefulness of HIV positive people, and the support they could provide. One lay counsellor said his attitude towards HIV positive people had changed as a result of his work:

So, another issue is that one of meeting the support group of the infected. When you meet those people, sharing their problems you will realize, even yourself you have problems, whether you are positive or negative. They can also help you to solve your own problems. That is where I am enjoying most, and I become relieved every day - any time when I am with them.　　　　　　　　　　　　　　*Lay counsellor 1*

Since unemployment was high in the area of study, holding a paid job was an important way for the health care workers to feed their family. It was also a sign of status in the community. In addition, they felt that they helped reducing poverty in the community by assisting HIV positive people through distributing food parcels, grants and other practical and material care. The work title and cooperation with the formal health care system also gave the volunteers, such as home-based carers, higher status and feelings of personal reward.

Home-based carers found meaning in caring for ill and dying patients as long as they could assist their patients in *"dignifying the death"*; meaning that they could assist the patient to die a peaceful death at home:

> *You must dignified the death, that she died under your care. Of which is a good thing, to die in a peaceful way, because we as human being, we must die in a peaceful way, in a dignified way. We must just not die like the animals.*   Home-based carer 3

Negative emotional experiences

Emotional exhaustion

All the health workers reported feelings of emotional drain, including being stressed, exhausted, strained and overwhelmed. They told of on-going pressure that led to emotional exhaustion and for some, (thoughts of) giving up their jobs:

> *You end up stressing your self, end up straining yourself. And which we don't like, because people will be saying, no, this is a difficult job, we don't want it any more, because of the pressure, is too heavy.*   Lay counsellor 3

Several said they were not adequately prepared to deal with the emotional reactions, needs and demands, and the deteriorating health and inevitable death of their patients. They also experienced difficulties in dealing with their own emotional reactions. One lay counsellor reported that he got personally involved in his patients lives to such an extent that it made him depressed. The home-based carers, in particular, experienced feelings of guilt, blame and despair related to the poor health condition of their patients. They reported that seeing the symptoms of their patients sometimes made them cry and that trying to care for terminally ill or dying patients, who literally died in their hands, was traumatising. Sometimes, the family of the patient would blame the home-based carer for the patient's death:

We don't spent much time with the patient or taking care of him or maybe give some medication and trying to heal him, we don't get that time. They just given us someone who is terminally ill. You can't spend time with him cause he will pass away within a week, myself it gives me a problem, cause many patient died in my hand, you find that it is a problem. (Shivering voice).   Home-based carer 1

One of the most stressful aspects of providing HIV/AIDS related health care services was the rapid increase in the patient load and the lack of resources. This was especially true after the introduction of antiretrovirals. Of special importance were the lack of basic medical equipment; the lack of sufficient locations for VCT and patient consultations; the lack of telephones, computers and faxes; and the lack of wages and means of transport. Many of the health care workers felt responsible for and guilty about having to shelve necessary tasks or send patients home without consultation. The lay counsellors would frequently feel compelled to skip their breaks or work overtime, without extra pay, and with negative consequences on their job performance:

To see all the patients, neh? It's like eh…we just categorize the clients, like this one is about to leave, maybe the ANC client, then we'll, we'll see you first. (…) And then, at the end of the day, let me say after 12, at this time, I'm totally exhausted. I want to rest. Sometimes I don't eat there. Even at lunch. (…) At 4, there is another people coming to the clinic. As if they have been off loaded by a bus there.   Lay counsellor 2

"Professional Accomplishment Impossible"

All of the health care workers complained that they were not able to provide quality services. The waiting time for patients was long, and many patients could not be attended to. Instead of individual counseling and information, group sessions were practiced at several clinics, with the risk of patients not hearing or understanding the messages conveyed. Individual counseling had to be given as briefly as possible. Everyone told of work duties increasing on a daily basis, just to be shelved at the end

of the day. One lay counselor reported that the perceived quality of the counseling, as well as his professional integrity, was compromised:

> It's about the quantity of the job we are doing, it's not quality. Because it is not advisable to see almost 30 people a day, it's not advisable. You need to see almost 4 or 5 people a day - that is enough. (...) Because it shows that if you see 30 people a day, you are only giving a person 5 minutes. So the only thing is that we have to sit down with the organizations we are working for, show them the right thing, that 'you know, you sent us to the people so that we can deliver, so but what you are expecting us to do, it's not the service delivery you were expecting, because we are going to do wrong things, and at the end of the day, I will be giving out 30 names. Just to show you that I am working. But I am doing nothing at all!*   Lay counselor 4

The health care workers felt that their work situation was too inflexible and unpredictable. The lack of perceived government support and a feeling of being *"left on our own"* were evident throughout the focus group discussion. They complained about the lack of involvement and effort from the government and NGOs, and accused such institutions of withholding money for wages, infrastructure and projects in the community. The supply of food parcels and grants was often delayed, which caused problems for the health care workers who were in direct contact with discontent HIV positive patients. The government was further criticized for the slow roll-out and shortage of supply of antiretrovirals, and for not promptly increasing staff to deal with the roll-out. There was a lack of staff at the tertiary hospital, especially doctors and social workers. The low number of staff meant that when colleagues were absent, more work would fall on the remaining health care workers, as there was little chance of finding a substitute. All of these factors contributed to the health care workers' perception of a challenging and uncontrollable work situation. The pressure was most acutely felt at the primary health care clinic level:

> We are supposed to provide quality service. What is quality? We are always in limbo, compromising. I feel so tired.   Nurse

The health care workers reported that they were often not consulted when HIV/AIDS service delivery policies were planned. For example, a nurse said that the 'supermarket style' of service delivery *"was imposed on us by the government".* The clinic staff complained that information from the hospital or government often did not reach them, with possible dire consequences for health care delivery. Many of the health care workers did not feel that their work was being appreciated, that they were not sufficiently paid and trained, and that they were being *"abused"* by the government:

I think it is time now to talk to our Government to stop abusing people. Volunteering of South Africa it does not mean we are slaves of the Government.   Lay Counsellor 4

Lack of sufficient training, especially among the home-based carers and lay counsellors, was rated as a serious problem. Several of the lay counsellors reported feeling insecure in their roles due to insufficient training and experience. The psychological aspects of counselling were particularly challenging. Challenges included dealing with strong emotions in patients (and self); how to assist patients in opening up and accepting their status; how to promote disclosure; and how to motivate HIV positive patients to live healthy lives.

The challenging interactions between patients and carers

Many of the challenges in patient- carer interactions were related to the common perception that HIV/AIDS was different from other diseases. One lay counsellor suggested that people's fear of HIV/AIDS was due to ignorance and lack of education. Others added that the fear also was related to the fact that HIV/AIDS is incurable. Talking about HIV was compared to talking about *"death and a grave".* The challenges mainly arose from the stigma and denial still attached to the disease:

The problem is the stigma is attached when coming to HIV…You know, the services are accessible but it is very hard for them to accept those kind of things because of the stigma attached. (…)   *Lay counselor 3*

All the health care workers in this study were aware of the complex impact HIV/AIDS had on their patients' lives. In addition to having an HIV positive diagnosis, the majority of the patients struggled with unemployment, low educational attainment, poor housing, lack of nutritious food, lack of money, and family problems. The health care workers often felt hopeless that they had little to offer patients with HIV/AIDS:

Most of them they like to talk a lot about money and food. So in most of the times we tell them that it will be okay one day, cause if you tell them there is no food, they will tell you not to come back again cause you are not helping them with anything.   *Home-based carer 1*

The lay counsellors and home-based carers accused professionals in the tertiary health institutions of frequently showing neglect, acting arrogantly and even hostile towards HIV positive patients. Anecdotes were told about nurses telling patients to go home and buy coffins because they would die soon, patients being refused grants from social workers and magistrates because *"they looked too well"* and patients having to disclose their status to managers to be able to retrieve their files from hospital officials. Nurses were blamed of having an 'attitude' towards patients. Nurses we spoke to during the project period admitted to sometimes acting rude and shouting towards patients, and blamed it on the unbearable workload, rude patients and a culture of *"showing off their status"*. The focus group reported that complaints from patients mainly involved lack of confidentiality. Both nurses and home-based carers were accused of disclosing patients' status without their consent. The focus group stated that the home-based carers' disclosure was due to lack of training, whilst nurses would disclose because of 'attitude':

Some of the nurses they got negative attitudes towards the client, you see… (…) -they shout (at) the client, and some you find out that the client is staying in M.,

he or she cannot come to M. (...) she rather go to the other clinic, fearing that that nurse or those nurses at the M. clinic they are doing so and so and so (...). So people they might fear to come because they know me, they think that maybe, if I can tell her, and they are afraid that if they tested positive, I can give information to others, can you see?   *Nurse*

As the range of HIV/AIDS related services expanded, more patients started requesting them, which meant that the clinics and the hospital experienced a heavier workload. At the start of the project period, most patients were female. With the availability of antiretroviral treatment and increasing delivery of disability grants and food parcels, more men came for consultations. Both the nurses and the lay counselors had experienced that some people became disappointed when their HIV test turned out to be negative. They would come back for tests later, hoping to be positive and thus qualify for a grant. Some would also 'shop around' for services at different clinics, thus 'occupying' valuable time and resources. Some of the health workers expressed feelings of powerlessness and fatigue in their meetings with HIV positive patients who were sometimes rude and demanding; expecting to be helped with everything from housing, food to emotional support, medicines and grants. Some men had even physically attacked or threatened health workers to receive grants, food parcels or medicines.

You see meeting people like us, is a very big challenge, because some of us we are coming maybe in a counselling room, having this negative attitude, knowing that I am HIV positive -I need to be cared and whatever I need, I have got to get, and all of those things.   *Lay counsellor 3 (HIV positive)*

On the other hand, some people did not believe that HIV/AIDS existed. Instead they would seek traditional explanations and treatments for their symptoms. Health workers noted that it was often difficult to motivate these patients to take an HIV test or to seek medical attention at an early stage of the disease, before their symptoms were pronounced. Some patients would deny their HIV status; not heed the recommendations given; or would frequently stop taking medicines when they felt better, despite medical advice. If patients chose not to disclose their status it could often be difficult to give appropriate medication or advice. Nurses and lay counsellors

stated that most men would be in serious denial rather than accepting their HIV positive status. Some of the health workers related stories of men who committed suicide or killed themselves and their partners after finding out that they are HIV positive. The wide variety in the patients' perceptions of the nature of HIV/AIDS, their views of what constituted correct treatments and the denial of many patients were sources of stress for the health care workers.

The need for debriefing and emotional support

There was no operating system of debriefing or support for the health care workers. A previous attempt to provide organized debriefing fell apart due to the workload at the health care locations. Also, time and costs for transport in this geographically dispersed area had made a common debriefing effort infeasible. However, all health care workers felt in need of debriefing and support. Many counsellors did not have the opportunity to share their burdens with colleagues, either because they worked alone or because work relationships were not conducive of this kind of sharing. For those who had the opportunity, the most common practice for debriefing (de-stressing) was to talk to colleagues, sharing problems and experiences and using humour as a coping method:

> *Then this thing of debriefing, let me just speak of my case- we are actually using these other counsellors. (…). So, I just share with them, I have another guy there who is good in making the jokes. After making the jokes, then I am good. (Laughs) That is a stress reliving method. So that is how I am trying to cope.*
>
> *Lay counsellor 2*

The health care workers reported that they needed training related to psychological aspects of care. Their main concern was how to deal with strong emotional reactions in their patients. They requested help to deal with patients in denial; to help patients open up; to adequately deal with strong emotional reactions; to give useful advice concerning disclosure.

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Discussion

The health workers described a work situation marred by lack of resources, increasing health provision demands, lack of training and support, limited government involvement, and a constant emotional overload. They felt emotionally exhausted; with limited possibilities of professional accomplishment and recognition; and they felt that the interactions with patients were demanding and sometimes cruel. The experiences they described were compatible with symptoms of burnout. Persistent lack of resources, training, basic medical equipment, governmental support, adequate communication, and coordination exacerbated the perceptions of powerlessness and burnout among health workers. A strong relation between job-related stressors and burnout has also been found in other studies (Schaufeli & Enzmann, 1998).

Emotional exhaustion has been connected to over-involvement in clients' lives and constant contact with emotionally demanding, often critically ill patients (Held & Brann, 2007). Our results confirm this, yet also points towards possible buffering effects of idealism, the finding of benefits in care-giving tasks, and *"love for the job"*. Finding meaning in care-giving can be a powerful way to achieve a balance between the costs of care-giving and personal reward (Carlisle, 2000). Benefits could include perceptions of personal growth, positive changes in personality, better understanding of HIV positive people, development of new relationships, perceived achievements and satisfaction with oneself, and altered priorities and goals in life (McCausland & Pakenham, 2003).

The reported difficulties related to dealing with emotions were also reflected in informal conversations and observations the authors made at the hospital. Nurses and lay counsellors we observed would encourage patients to be strong and not to *"dwell on their problems"*. When clients demanded more counselling or support, they were often referred to as *"making fuzz and taking too much time"*. Time constraints, a huge workload, and lack of training can partly explain this behaviour. Also, as noted in other studies, counsellors simply felt their services were inadequate as they did not have answers or did not know how to help their HIV positive patients (Richards & Marques, 2005). Expression of emotions is encouraged in counselling sessions. Yet the Sepedi culture encourages restrained expression of

emotions, and do not see them as separate subjects of discussion (Magubane, 1998). This conflict between traditional culture and the modern health care 'culture' has also been reported in other studies (Jackson & Sears, 2001; Dageid & Duckert, in press). To 'open up' might traditionally have required more time and familiarity with the health care provider, yet time was in short supply in most counselling sessions.

The health workers in this study experienced limited professional accomplishment and recognition, and felt that much of the work they performed was insufficient and of low quality. This seemed to be particularly true for the clinic-based nurses who had to give quality care to a range of patients, not only the HIV positive ones. The nursing profession has often been described as having a second-rate status, with an overload of responsibility yet little influence in decision-making processes (Hirschhorn & May, 1999). In accordance with Mackintosh and Tibandebages (2000) study, we observed that nurses at the hospital felt overloaded and sometimes abandoned by doctors formally responsible for HIV care. Doctors were in high demand, and could work at several hospital wards a day, or have their own private practice in the afternoons. Several days during the project period, the lack of doctors halted the service provision of nurses, lay counselors and social workers, causing frustration in the system.

Nursing and teaching were the only possible professions for Black women under Apartheid. Nurses thus enjoyed a high status in their communities (Jewkes et al., 1998). With democracy and opening up of the job market, nursing no longer holds a privileged status. This might explain some of the frustrations of the nurses when it comes to professional accomplishment. Lay counselors and home-based carers, on the other hand, might not have that much status to 'loose'.

Aggressive behaviour is one of the classic reactions to stress (Payne, 1999). The reactions from health workers towards patients described in this study fit other findings on depersonalization related to burnout (Smit, 2004; Benevides-Pereira & Alves, 2007). Some claim that the rude behaviour of nurses towards patients is related to insecurity about their clinical roles, perceptions that their status is being undermined, and an underpinning ideology of patient ignorance and inferiority (Jewkes et al., 1998). However, none of the health workers we spoke to mentioned cold, impersonal, indifferent or rude behaviour from lay counselors towards patients, even though they too experienced insecurity, stress and feelings of

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inadequacy in relating to HIV positive patients. The explanation could lie in the difference between the lay counselor role and the other health caring roles. Home-based carers usually have minimal training in dealing with emotions or psychological needs in their clients. Theirs is a physical, often palliative, caring role. According to Van der Walt & Swartz (2002), public sector nursing in South Africa follows a task-oriented approach that does not adequately focus on the emotional experience of illness. Petersen & Swartz (2002) argue that a task-oriented approach may be at odds with patient empowerment and comprehensive care, due to its technicist nature. Lay counselors on the other hand, are trained in this client-centered, holistic patient care approach, which may enable them to communicate with the patients more effectively, thus protecting them against developing depersonalized attitudes and behaviours. The focus group participants mentioned lack of training as a risk factor for health workers' disclosure of patients' status, improper behaviour, prescription of wrong medications or provision of incorrect counselling.

As found in other studies (Smit, 2004; Orner, 2006), health care workers in our study reported reactions such as emotional exhaustion, despair, helplessness, depression and aggression. They reported that they needed training related to psychological aspects of care. At the same time, their own needs for emotional support and debriefing were unmet. There is obviously an urgent need to identify early symptoms and avoid the development of burnout, and if present, to establish ways of reducing the effects of burnout on health care workers.

What can be done?

The first author, who is a trained psychologist, observed a huge, unmet need for emotional support and counseling among the HIV positive patients she met through the hospital clinic. At the same time, several health care workers were requesting professional help to deal with patients in denial; to help patients open up; to adequately deal with strong emotional reactions; to give useful advice concerning disclosure; and advice on how to start up support groups for HIV positive people. As reported in several studies, HIV positive people are usually more concerned with the psychosocial consequences of HIV than the medical aspects (Lie & Biswalo, 1996;

Dageid & Duckert, in press). A client-centered approach might be even more needed after the introduction of antiretroviral treatment, since patients are expected to live longer and thus would need counseling and advice on 'positive living' over a longer period of time.

In a stretched work situation, who will care for the carers? On a systemic level, there is a need to increase the number of staff; improve provision of equipment; improve the wages and status of health workers; employ more assistant or semi-skilled labour; improve the working relationship between nurses and doctors; provide more training opportunities in for example stress management; and improve government commitment and involvement. Of course, many of the systemic short-comings are symptoms of national priorities, overall lack of resources, and historical inequalities that are not changed over night. The government is making progress, and it is only to be hoped that it will continue to increase its involvement and commitment to improving the situation for HIV/AIDS in general and health care workers in particular.

On the ground level, much can be done to improve the health care workers' situation. Firstly, the need for emotional support must be recognized and appropriate, sustainable and debriefing mechanisms put in place. Despite being overburdened with caring duties, time and resources should be set aside for health care workers to receive regular, professional debriefing and guidance. As indicated by the result of this study, debriefing should mainly focus on the emotional challenges facing health care workers; such as anger, death, loss, grief, and depression; and provide the health workers with 'tools' to cope with such emotions. At the same time, mechanisms to enable and support personal and professional growth, for example receiving praise and recognition for tasks accomplished (Orner, 2006) ought to be an integral part of every-day work.

The 'continuum of care' necessitates new ways of thinking about provision of HIV/AIDS care and support. HIV positive people are not only "victims". Many of them are resourceful and could be encouraged to take a greater part in the provision of health care, such as raising community awareness, providing information and emotional support, and sharing experiences about services and resources for HIV positive people. Openly HIV positive community members might also encourage other people to seek medical attention in the early phases of HIV/AIDS, thus

improving patients' quality of life and reduce health complications and related burdens. The establishment of support groups could be a useful, systematic step towards relieving the overburdened health care workers of some of the 'lighter' care and support tasks. The HIV positive people involved in this larger project formed such a support group, which actively assisted the health care workers in identifying, informing and supporting other HIV positive people emotionally and practically (Dageid & Duckert, submitted). One of the most successful events was arranged by the support group, in partnership with health care workers, to inform the community about the introduction of antiretroviral treatment. The event gathered around 400 people and was attended by stakeholders from the government, NGOs, churches, schools and the health care services.

People often find it more appropriate and useful to receive support from colleagues than from 'experts' or supervisors. Health workers may thus benefit from forming their own support groups or teams where they can vent and discuss the emotional challenges they experience. In such groups, they might also find some respite from heavy care taking duties through for example arranging social events (Smit, 2004; Held & Brann, 2007). Support groups could be useful additions to a more professional guidance and debriefing service.

In conclusion, 'caring for the carers' is an important activity that may reduce the risk of burnout; diminish the rate of drop-out among health workers; encourage continuity and quality in services and promote a healthier workforce.

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