

The experiences of Batswana families regarding hospice care of AIDS patients in the Bophirima district, North West province, South Africa

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Abstract

The HIV/AIDS pandemic put significant strain on healthcare services in the country. Hospitals were no longer coping with the escalating number of AIDS patients. This resulted in the early discharge of patients, with some patients, too ill to be nursed at home, being sent to hospices for continued care. The Batswana had mixed feelings about hospice care, because their beliefs on patient care are based on the ubuntu philosophy, which emphasises the principle of caring for one another. The purpose of this study was to explore and describe the experiences of Batswana families regarding hospice care for patients in the Thlabane township in the province of the North West as well as to make recommendations to policy-makers to ensure that hospices are accepted by community members and utilised effectively. A qualitative, explorative, descriptive research design was applied. Purposive sampling was applied to select study participants with whom in-depth unstructured interviews were conducted. A qualitative data analysis was done by categorising, ordering, and summarising the data, and describing the findings. The findings indicated that families of patients in hospice care experienced such care as foreign to their culture. These families also experienced stigmatisation, firstly owing to the stigma associated with AIDS and secondly because they opted for hospice care. However, they also observed the high quality of care provided by the hospice and understood its benefits for AIDS patients. The study concluded that hospice care relieved families of terminally ill AIDS patients of the burden of care and enabled them to keep on working and earning a living. Recommendations to policy-makers included enhancing hospice care and ensuring the provisioning of culturally safe hospice care.

Keywords: *experiences, Batswana, hospice care, AIDS, ubuntu philosophy*

Résumé

La pandémie du VIH/SIDA a mis une forte pression sur les services de soins de santé du pays. Les hôpitaux ne pouvaient plus faire face au nombre croissant de patients atteints du SIDA. Il en a résulté la sortie précoce des malades du SIDA, avec certains patients trop malades pour être soignés chez eux, envoyés aux hospices pour des soins continus. Les batswana avaient des sentiments mitigés au sujet des soins palliatifs, parce que leurs croyances sur les soins médicaux sont basées sur la philosophie ubuntu, qui met l'accent sur le principe de prendre soin de l'un de l'autre. Le but de l'étude était d'explorer les expériences et de décrire les expériences des familles de Batswana en ce qui concerne les soins palliatifs pour les patients habitant le canton de Thlabane dans la province du Nord-Ouest, mais aussi de faire des recommandations aux décideurs politiques pour s'assurer que les hospices sont assurés par les membres de la communauté et utilisés efficacement. Une conception de recherche qualitative, exploratoire, descriptive a été appliquée. Une méthode d'échantillonnage raisonnée a été appliquée pour sélectionner les participants de l'étude avec lesquels des entretiens approfondis non structurés ont été menés. Une analyse qualitative des données a été faite par la catégorisation, la commande et le résumé des données et la description des résultats. Les résultats de recherche indiquaient que les familles des patients en soins palliatifs prenaient de tels soins comme étranger à leur culture. Ces familles ont également connu la stigmatisation associée au SIDA et en second lieu parce qu'ils ont opté pour les soins palliatifs. Cependant, ils ont observé la haute qualité des soins dispensés par le centre de soins palliatifs et compris ses avantages pour les malades atteints du SIDA. L'étude conclut que les soins palliatifs soulageaient les familles des sidéens en phase terminale de la charge des soins et leur a permis de continuer à travailler et gagner leur vie. Les recommandations à l'intention des décideurs politiques incluaient l'amélioration des soins palliatifs et d'assurer l'approvisionnement des centres de soins palliatifs culturellement sécuritaire.

Mots clés: *expériences, Batswana, centre de soins palliatifs, SIDA, Philosophie ubuntu*

Introduction

Hospice care is a well-established approach to palliative care. Through focusing on the patient rather than emphasising the disease, hospices enabled countless people worldwide to die with dignity. The hospice approach ensures that patients spend

their last days in an environment where their pain is minimised and comfort is maximised (Cameron 2009:1). However, among Africans the idea of admitting a patient to a hospice is frowned upon, as the custom is that people care for their loved ones until

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death (Watson, n.d.:51). The family structure is viewed as a place of care, and people bear children so that the children can take care of them in their old age and when they are frail and sick.

The Batswana share the values and cultural norms of other African communities. They believe institutional care makes one lose one's sense of belonging and independence. African people, including the Batswana, take care of vulnerable groups like children, older persons, and the sick and dying, by looking after them at home (Ott 2009:3). To let a person die in a strange environment is taboo and, therefore, terminally ill patients, as well as terminally ill AIDS patients, should be cared for by members of their own families at their own homes. If families encounter difficulties in this regard, the significant others as well as the members of the community will in solidarity offer their assistance.

This view is supported by the African philosophy of ubuntu. The term 'ubuntu' is derived from an isiXhosa idiom which reads as follows: *'umuntu ngumuntu nga bantu'*. The Setswana equivalent is *'motho ke motho ka batho ba bangwe'*. The literal English translation is 'a person is a person through other persons' (Broodryk 2006:17). Ubuntu is generally described as a worldview of African societies, and a determining factor in the formation of perceptions that influence social conduct. Ubuntu has also been described as a philosophy of life, which in its most fundamental sense represents being, humaneness and morality. This view ultimately has an impact on one's death, hospitalisation or institutionalisation. From this premise the Batswana believe that people must look after each other in sickness and health. Caring involves all the members of the community, including the immediate and extended family, other relatives, and neighbours. In an African community, life is lived in a group or tribe. In this communal way of life, solidarity and collectivism are emphasised and practised (Masango 2005:918). Family-centred care is a core value of the Batswana.

Although the Batswana communities may have strong sentiments on family-centred care, the way of living has changed drastically in recent years due to the modernisation of society. People no longer live as extended families. Nuclear families are becoming the norm. Women are emancipated and work full-time and older persons and the sick are often left to cope on their own while adult breadwinners are at work (Hotep 2003:7). This new way of living left many families with no choice but to have their terminally ill loved ones admitted to a hospital or hospice for care.

In developing countries, the HIV/AIDS pandemic placed a large burden on public health facilities that already functioned with limited resources. As hospitals were already stretched beyond their limits, home-based care became the central concept in the provision of care to HIV/AIDS patients (Ncama 2005:33).

Hospices in South Africa have been catering for terminally ill patients suffering from diseases such as cancer for many years. According to Gwyther and Rawlinson (2007:4), hospices have been used to care for AIDS patients in South Africa from the 1980s, with the aim of relieving caregivers of the load of care. However, hospices were only used by certain population groups, not including the Batswana. In recent years, owing to changing lifestyles and disease patterns such as HIV/AIDS,

African communities, including the Batswana, have also allowed their family members to be admitted to hospices for care.

Case studies conducted by African Comprehensive HIV/AIDS Partnerships (ACHAP) in Botswana on the perceptions of the Batswana regarding home-based care revealed that most people welcomed and preferred the home-based care option because the home-based care model was perceived as upholding the cultural norms of African communities (Watson n.d.:51). The same study argued that home-based care did not meet all the needs of all patients owing to the fact that home-based caregivers could not be with patients at all times, depriving these patients of continuous care. Hospices thus became a necessary care alternative. Hospice care was initially unknown to many communities; it was a phenomenon they had to learn to accept. Family members had different views on hospice care and its acceptability within a community. This research article describes the experiences of Batswana families who allowed their terminally ill family members to be admitted to a local hospice for care.

Extent of the problem

HIV/AIDS has adversely affected the socio-economic status of many countries, including that of South Africa. Worldwide at present 40.3 million people are estimated to be living with HIV/AIDS (USAIDS 2004:19). Africa is inhabited by just over 12% of the world population, but it is home to 60% of the AIDS-infected population. In South Africa, an estimated 5.3 million people are living with HIV/AIDS. South Africa, as part of the sub-Saharan region, has inherited most of the challenges that this region is now facing, including the HIV/AIDS pandemic. In 2004, USAIDS (2004:19) predicted that deaths in the region would, until 2010, rise sharply as a result of the pandemic and inadequate resources such as beds in hospitals to deliver care. Giarelli and Jacobs (2006:1) subsequently confirmed that the HIV/AIDS pandemic reached unprecedented proportions in sub-Saharan countries.

In the province of the North West, an estimated 329 000 people were living with HIV/AIDS (Noble 2007:2). This province is predominantly occupied by several Batswana tribes, including the Bangwato, Bakgatla, Bafurutshe, Bangwaketse, Bathlaping, Barolong, and Bafokeng. The study was conducted in the Bophirima district that houses only one public hospital. As there are no district hospitals in the area, patients from surrounding districts are admitted to the one public hospital.

In recent years, this single public healthcare facility had to cope with an increasing number of patients, including terminally ill patients, because of an increase in the number of people, especially migrant workers, in the area (Noble 2007:3). Migrant labour in this part of the country is mainly due to the mining industry – the major source of employment in the province. Migrant workers who were separated from their families seemed to be susceptible to extramarital affairs, which is an apparent cause of the increase in the rate of HIV/AIDS infection among this subgroup. In 2001, the South African government assisted by non-governmental organisations erected two hospices in the province to facilitate the delivery of quality care to HIV/AIDS patients who could not be cared for at home. Families who could not continue to care for their terminally ill family

members suffering from AIDS were advised to consider the hospice care option.

The construction of these hospices evoked mixed feelings among the Batswana about the acceptability of this form of care. This study aimed to explore and describe the experiences of Batswana families regarding hospice care for family members suffering from AIDS, with a view to making appropriate evidence-based recommendations to government about enhancing hospice care and its acceptability to the Batswana.

Research design and research method

A qualitative, exploratory, descriptive study was conducted because the researcher intended to explore and describe the experiences of Batswana families in the Bophirima district on hospice care for family members suffering from AIDS. Exploratory, qualitative research is designed to shed light on the various ways in which a phenomenon manifests itself and on the underlying processes (Burns & Grove 2005:27). The target population consisted of Batswana families who had a family member suffering from AIDS being cared for in a hospice. A purposive sampling method was used to select the study participants. The study participants were made up of volunteers who complied with the inclusion criteria for selection. The sample was drawn from those in the target population who registered their terminally ill family member for hospice care for 3 months or more. The researcher presumed that they would be sufficiently involved to state their experiences about hospice care. The researcher had no choice but to consider this relatively short duration of registration, as nearly all AIDS patients admitted to hospices are terminally ill with poor prognoses. The researcher visited homes with the aim of obtaining consent and conducting interviews. She allowed families to choose the primary care giver to participate in the study. The majority of the participants were mothers and wives of the terminally ill. Families agreed to sign the consent form for participation in the study. Members of five families were included in the pilot study. Data were collected until saturation was reached. Ten families participated in the actual study from which conclusions were drawn.

Data collection

In this study, data were collected through unstructured interviews conducted in the family members' home environment. This arrangement enabled the participants to relax and freely express their experiences – requirements that were vital for this study. A dense text was obtained when the illustrative quote or voice of the participants recorded during interview sessions was transcribed. The interviews were conducted in Setswana, transcribed, and translated into English. The following central question was asked:

What are your experiences as a family regarding hospice care for AIDS patients?

A tape recorder was used to ensure that all data were captured. The interviews were conducted in Setswana and translated to English by a qualified language practitioner to ensure that no

meaning of data are lost. The researcher transcribed the audio-taped interviews.

Trustworthiness of data were ensured by addressing the credibility, transferability, dependability and confirmability of the results. Transferability was ensured by asking participants to provide elaborate descriptions of their experiences of the phenomenon and to provide a full description of the context and setting of the study. Credibility was ensured by using two independent coders to analyse the data. Member checking was also done to verify the findings with the participants. To ensure dependability the researcher documented all the raw data.

Data analysis

The transcribed and translated data were coded and categorised, and relationships were developed between the categories. From these relationship patterns, the behaviour and responses of the participants were identified (Burns & Grove 2005:561). Tesch and Tesch's method of data analysis were used. According to Brink, van Rensburg and van Der Walt (2006:170), the data analysis method entails categorising, ordering, manipulating and summarising the data and describing them in meaningful terms.

Ethical considerations

The purpose of the study was explained to the sub-district health manager of the Bophirima district in the North West province, who then gave permission for the research to be conducted. Permission was also obtained from the management of the Tshupe Hospice. The researcher observed the following ethical considerations throughout the study: obtaining permission from authorities to conduct research; obtaining informed consent from participants; maintaining confidentiality and anonymity; avoiding the exploitation of participants by ensuring voluntary participation; and ensuring the protection of human rights and freedom of choice (Burns & Grove 2005:83).

Findings of the study

Major categories that emerged from the interviews with participants who expressed their experiences regarding hospice care for AIDS patients were the following: 'hospice care foreign to culture', 'social stigma associated with AIDS', 'differences in healthcare practices', and 'knowledge is power'.

Hospice care foreign to culture

The study participants described hospice care as foreign to their culture. The term 'foreign' means something that is introduced or brought in from outside, i.e. from another country or another culture, in other words, something unfamiliar or uncharacteristic (South African Concise Oxford Dictionary 2002:1367). One of the participants said:

It is not within our culture to subject an ill person to an unfamiliar environment when he needs us badly during an illness.

According to the participants, hospice care was totally different from the traditional line of thought or way of doing things in the community. The Batswana, like most other African communities, subscribed to the ubuntu philosophy, which maintains

that, in case of illness, the family has to take care of their loved ones at home. Although the concept of dying in a hospital was accepted by many communities, taking or sending your loved one to a hospice for care was still viewed with scepticism. Participants asserted that sending a patient to a hospice for care might result in family conflict. Even though the hospice care option was discussed by family members and agreed upon, inability to care for a loved one would cause disharmony within a family. Confusion and misunderstanding were rife among family members who lacked knowledge of this approach to care. Participants indicated that having their loved ones admitted to a hospice created problems such as criticism from husbands, mothers-in-law, the extended family, and neighbours.

They verbalised that although they had harmonious relationships before taking their terminally ill family member to the hospice, disapproving family members would react negatively afterwards. It was found that the mother of the patient was usually blamed for the family's decision to opt for this form of care. The father of the patient, or even the grandmother, would change their attitude towards the mother, even though a consensus decision was initially reached. The following statement was explanatory:

In the beginning my husband did not even talk to me because he believed that I had rejected his son, even though he once agreed on that [hospice care]. Maybe it's because he was not in favour of the whole idea from the very beginning.

Even the extended family would criticise the hospice care option after initially agreeing to it, as could be inferred from the following quotes:

When I took my son to the hospice, conflict and disagreement arose among the members of the extended family as though we had never discussed this issue within the family.

My sister-in-law was the one spreading rumours about my insensitive and uncaring attitude. She said I waited for her brother to pass on, so that I could do as I please.

It became increasingly clear to one of the study participants that her family members were not buying into the hospice care option, making her unsure about the way forward. In many instances, conflict developed among family members when other people they related to, such as neighbours and significant others, would show their disapproval of the hospice care option.

Participants were concerned about changes in the attitudes and behaviour of neighbours who had become aware of the terminally ill patient's admittance to a hospice. They, the neighbours, felt uncomfortable around a person who supports foreign ways of doing things rather than taking care of her sick child. One participant explained their strained relations as follows:

My neighbours do not visit me as they did in the past. Even if one would come, she would not drink or eat anything from my house as if everything was filthy or could infect her. This continued until one of the caregivers from the clinic came and

clarified issues, such as how one gets infected, with some of them.

Africans believe in doing things together; they value their relations with all people in the community, including their neighbours. This is evident by the way in which people greet each other. They always want to know about the status of one's health. The particular 'good morning' or 'good afternoon' is always followed by 'How are you doing?' ('le kae?' in Setswana).

Social stigma associated with AIDS

Social stigma associated with AIDS emerged as a data category from the study. Linsk and Gilbert (2007:3) defined social stigma associated with AIDS as a feeling of rejection and grief that resulted from the AIDS status becoming known. In this study, the families of AIDS patients bore the brunt of social stigma. A major cause of stigma was the fact that patients were transported to and from the hospice by a hospice vehicle identified as such and, while the hospice catered for any terminally ill patient, it was known to cater predominantly to AIDS patients. During the interviews, participants revealed feelings of guilt and anger which led to anxiety. Feeling stigmatised also evoked feelings of guilt, self-blame, regret, and self-pity. These feelings were reflected in the following comment by a participant:

Initially I did not really trust hospice care at all for my child. I felt ashamed of the decision I took. Circumstances forced me to take my child to the hospice for care . . . it felt as though I was rejecting her.

Participants conveyed that their ill family member also felt rejected when admitted to the hospice for care. Participants also believed that it appeared as though they were rejecting their loved ones. The feeling of rejection experienced by patients and families was mainly attributed to the stigma associated with AIDS, with hospice care having a direct bearing on AIDS stigmatisation. A participant explained further stigmatisation by opting for hospice care as follows:

Now people see you; you are put in an institution and you stay there with only people like that [other AIDS patients]. In a way this is a stigma on its own.

According to participants, they experienced stigmatisation not only because of the AIDS issue, but also because of the hospice care option that aggravated matters. Participants believed that stigmatisation could be lessened by changing attitudes through enhancing knowledge and understanding. One participant expressed her feelings about stigmatisation as follows:

I think the struggle, the main, main struggle was the issue of my son being picked up and dropped off with the car on which 'hospice' was written. I felt angry and concerned about what the neighbours would say.

Participants revealed that, because of the stigma attached to AIDS, some people believed that patients should be kept at home and be nursed secretly. According to the ubuntu philosophy, people are best taken care of at home. The philosophy was applicable to

people with all types of disease but, owing to stigmatisation, especially AIDS patients. Participants believed that a hospice would only expose the AIDS patient to the 'outside world' – to strangers whose reactions might be unpleasant. The following statement explained this view:

Culturally, we usually take care of them [AIDS patients] at home. They don't get exposed a lot to the outside world, to other people. I think in our culture having AIDS is a bit of a stigma. So when they are HIV positive, all of a sudden people think that the signs are there, that people can see it, even though it is not written on your forehead. There is this thing that people can see, so people hide you in the house, they nurse you in the house and hide you till the end of your life rather than send you to the hospital or hospice. We also know that they look down on us, as we have a person with AIDS in our family. They talk a lot about us, quite a lot.

Differences in healthcare practices

The third major data category that emerged from the interview sessions was differences in healthcare practices between hospitals and hospices. Participants experienced the care that their loved one first received at the hospital as inferior to the care the patient was receiving at the hospice. While hospice caregivers showed love and compassion, hospital staff, according to the participants, lacked empathy and would often discharge patients from hospital before they were well enough to be taken care of at home. One participant said:

At the hospital, patient care was not good . . . the nurses today don't care for patients like the old nurses did – maybe they are overworked. We removed him from the hospital because the care was poor, and hospital personnel agreed. Someone recommended hospice care; the ward was so full that patients did not get individualised care.

Participants expressed their appreciation of hospice caregivers, stating that they experienced sympathy and warmth at the hospice during the stay of their loved one. They expressed their appreciation as follows:

I lack words to describe the care I saw being given to my child at the hospice. They received my child with warm hearts. The empathy demonstrated by the nurses was formidable. Nurses at the hospice are dedicated caregivers.

Participants were aware that hospice caregivers were knowledgeable about palliative care and caring for a terminally ill patient.

Knowledge is power

'Knowledge is power' was the fourth major category that emerged from the interviews. Participants believed they were more knowledgeable about the way hospices function due to their involvement with the hospice, and they felt empowered by obtaining that knowledge. While involved with the hospice, they learned more about AIDS as a condition, as well as the importance of

counselling that improved the emotional well-being of their loved one. They realised that emotional support was improving the quality of life of the terminally ill patient. The following comment was relevant:

What I have noticed is that they are counseled: they are taught how to take medication for the illness, what to eat, lifestyle choices, and to accept their illness. That is what I have noticed.

Participants expressed their gratitude towards hospice caregivers because hospice care apparently had a positive effect on patients' emotional well-being. According to the study participants, positive emotional changes in loved ones were the result of the counselling received at the hospice. Their loved ones understood their condition better and started to accept the outcomes. The attitudes of family members also changed as they gained a different perspective of hospice care. They expressed their appreciation and satisfaction because the hospice care option changed their lives in a positive way. According to De Figueiredo and Turato (2001:633), through counselling, hospice care, just like the home-based care initiative, seemed to be very successful in enhancing the human dignity of patients living with AIDS.

Uys (2002:101) explained that the hospice assessed clients' physical and psychological needs, and clients were given advice such as how to live with the disease. It thus became possible for terminally ill patients to improve physically. The author further stated that caregivers were able to offer basic physical care such as mouth care, bed baths, ambulation and health education that the client was not receiving elsewhere. These basic services also helped to improve the physical condition of patients

The following statement by a participant in this study confirmed the earlier observations by Uys:

He refused to eat or to take his medication . . . the hospice has helped me; all that is corrected. I am thankful for the improvement I see in my child. He has indeed improved after receiving hospice care because, at first, he could neither get out of bed nor sit.

Participants indicated that they also learned more about the treatment and nutritional needs of AIDS patients from hospice staff. Practical assistance, good nutrition, and personal hygiene received priority in the hospice, and these practices brought about the physical improvement in patients. During the interviews, study participants, particularly mothers of AIDS patients, related the rate at which their loved one was improving physically.

Willingness to advocate for hospice care

From the interviews held with participants, the theme 'willingness to advocate hospice care' emerged. Because participants discovered the good effects that involvement with the hospice had in their lives, they were willing to advocate hospice care; they wanted others in the community to also share in the benefits of this care option. They seemed to know which avenues to pursue so that the community could get the information they needed. The participants made the following proposals:

I think many people don't really get the idea of hospice care. So I think, when people go around, informing people about HIV/AIDS and what is done to prevent it, I think they should also teach people about hospices and hospice care. Maybe, if there were, say, two hospices in the township, maybe it would be better. Now there is one hospice. Maybe this should also be discussed in churches; people should talk about hospice care. Let people talk about it and then do something to help out, and then it won't be such a stigma, you know. Make the information available to people, teach people so that they learn and become aware, more open-minded, so that they become open-minded about the whole hospice idea.

A participant was aware that ignorance about hospice care was common among Black people, which was the reason why she named them as the target group.

I am personally willing to advocate hospice care and educate my fellow Black people to come out of the darkness of ignorance.

Participants in the study indicated that opting for hospice care freed family members from the burden of care and enabled them to meet other obligations. Many participants were sole breadwinners; they could not afford to stay at home and take care of seriously ill family members. They left their homes early in the morning to return late in the afternoon. The hospice served these families because patients were also fetched in the morning and brought back in the afternoon when family members could continue the care of these patients. A participant mentioned that the hospice, though culturally foreign, meant relief because they as a family could not provide home-based care. She felt that there should be more hospices, as she realised their worth:

My family is released from the bondages of cultural ignorance . . . there is a need for more hospices in our communities, as they bring relief to us.

Discussion of findings

The Batswana, like other African communities, were not used to the concept of removing a terminally ill family member from the family so that the patient could be cared for by strangers, albeit professionals like in a hospice. Wacharasin and Homchampa (2008:390) stated that Black people viewed hospice care as a Western approach to AIDS and cancer care, aimed at rendering end-of-life care, which was foreign to them and contradictory to their culture. In African communities where the ubuntu principles were practised, caring for each other was considered a family and societal effort (Brack, Hill, Edwards, Grootboom & Lassiter 2003:319).

Although the whole family would discuss the hospice alternative and agree on taking the ill person to the hospice for care, wives and mothers felt they were expected to take the blame when neighbours questioned the family's decision. Mothers were

mostly blamed for the family decision to take a child to the hospice because they were seen as the primary caregiver, the family pillar responsible for care. Even though they were included in the discussion and gave their consent, the extended family would say, retrospectively, that the mother ignored cultural practices by taking the terminally ill family member to the hospice. Leclerc-Madlala (2005:34) maintained that the role played by women as caregivers put them in a leadership position as far as the union of the family was concerned. For this reason, any conflict or misunderstanding was directed at them, even when illness and death occurred.

Participatory decision-making was the norm in the African culture. This view was supported by Watson (n.d.:52) who maintained that, in Botswana, when major decisions such as taking a child to the initiation school and on health-related matters had to be taken, the family would sit together and deliberate until a consensus decision was reached. Masango (2005:917) stated that the principle was based on communitarianism. He argued that, in societies where communitarianism stayed the norm, individualism and privacy were not taken into account in decision-making concerning matters such as marriage, the hospitalisation or institutionalisation of terminally ill patients, and death and dying procedures. Consultation and collaboration were emphasised, respected and valued. Failure to observe the norm resulted in discomfort and conflict.

The communitarian Batswana believed in consulting older persons in the family, in accordance with the ubuntu principle, before decisions were taken. According to this belief, older persons had the experience, and the interest of the family at heart (Masango 2005:918).

In an environment where communal practices were the norm, affirmation of your decisions by the significant others was valued. This cultural value is reflected in the isiZulu proverb 'Izandla ziyagezana' (hands wash each other). Africans maintained that people cared for one another and one person's problem became the community's problem (Mulaudzi, Libster & Phiri 2009:47). Words of criticism were taken seriously, just like words of acknowledgement and compliments. From this premise, the behaviour of neighbours and their attitude towards the individual became important and valuable. A negative change in their attitude might lead to the individual being excluded or isolated from community functions, ceremonies and community events (Masango 2005:918).

In researching the case of the Tonga in Zambia, Gausset (2001:12) found that people in the community looked down on those who had their AIDS patient hospitalised. Similarly, those not actively involved in the care and support of such a patient also found themselves shunned by the community.

The participants in this study showed signs of frustration owing to conflict and misunderstanding resulting from the decision to opt for hospice care. Family members still clung to the practice of caring for terminally ill patients at home, in accordance with the ubuntu philosophy, even though this practice, especially in the case of working mothers and sole breadwinners, was no longer feasible.

Brack *et al.* (2003:319) were also of the opinion that the ubuntu worldview of African societies was a determining factor in the formation of perceptions that influenced social conduct. The implication was that, if family members disapproved of decisions made regarding hospice care and believed there was a deviation from the norm, they would most likely cause conflict as was experienced by the participants.

The data analysis also revealed that some participants sent their loved ones to a hospice as punishment for not listening to their advice. According to Van Dyk (2001:4), some Christians believed that AIDS was God's punishment for immorality and sin. Illness as well as hospice care was seen as a penalty by some for their wrongdoing. AIDS was perceived as a 'dirty' disease, a disease associated with promiscuity. This misconception brought about condemnation and a belief that AIDS was a form of punishment (Van Dyk 2001:5). In a study by Duffy (2005:14), some participants denying that their relative or child had AIDS, blamed the ancestral wrath and witches for being responsible or causing the disease as a form of punishment. This culminated in hospices being perceived as places that were ungodly and catering for people who were being punished.

Other barriers to access and utilisation of hospices cited in literature included the inability of hospices to address issues relating to religion, spirituality, and culture. According to Char (2003:376), procedures within hospices were incompatible with or insensitive to the culture of African Americans. This sentiment was also expressed by proponents of the incorporation of culture into the healthcare system. Terms such as cultural safety, cultural congruent care and cultural diplomacy were applied and described in literature to show the importance of respecting the values, norms and practices of healthcare users (Eckermann, Dowd, Martin, Nixon, Gray & Chong 1992:215; Leininger & McFarland 2006:315). Mulaudzi *et al.* (2009:47) asserted that, in their daily contact with patients, healthcare professionals needed to display cultural diplomacy and the principles embedded in the African philosophy of ubuntu.

Families caring for AIDS patients needed psychological, social and emotional support. The study participants (family members of AIDS patients) experienced social stigma and feelings of guilt and anger. Even though they knew they could not look after their loved one full-time, they still felt guilty and started to doubt their decision to send the patient to the hospice for care. Dworzanowski (2002:426) maintained that families affected by and patients living with AIDS had lost their autonomy, privacy and control. They were haunted by guilt, denial and anger, and lacked coping mechanisms to combat anxiety, depression and suicidal thoughts. The inability of family members to look after the ill person intensified their feelings of guilt. The cultural beliefs and practices of communities and their lack of knowledge of hospices (Sullivan 2007:79) contributed to families' feelings of guilt about the decision to have their ill relative admitted to a hospice for care.

The stigma associated with AIDS created the silence on AIDS and the fear of ostracism, discrimination and rejection (Linsk & Gilbert 2007:4), which became major barriers to obtaining

assistance and medical attention. Suffering from the stigma of AIDS heightened the patient and caregiver's stress level (Orner 2006:238). In addition, Carr (2006:12) maintained that AIDS patients and their families were vulnerable as they feared rejection by the significant others. According to Harding and Higginson (2005:1972), the Spanish term for 'hospice' has a very negative connotation. It implies abandonment; some patients actually felt as though they were sent to a leper colony, a place from where they would not return. A hospice was viewed as a place that mainly dealt with end-of-life care; patients who were taken there also knew this, and often felt that their families had given up on them. This had a negative effect on patients, especially patients who still hoped for recuperation or cure (Johnson, Schierhout, Steinberg, Russell, Hall & Morgan 2002:1953).

A study about barriers to hospice use among African Americans by Washington, Bickel-Swenson and Stephens (2008:270) also found that patients who believed in God's healing power perceived being taken to a hospice as evidence that people had given up on the power of God. They held fast to their belief in God's healing power because hospices, unlike hospitals, did not offer vigorous types of treatment that to them could lead to healing. Char (2003:380), on the contrary, documented the issue of mistrust of modern medicine by AIDS patients. In rural Haiti, according to Fitzgerald and Simon (2001:308), AIDS patients had doubts about the types of medication administered in hospices. The fact that they would only be visited at scheduled times also made patients doubt this option of care (Char 2003:380). AIDS patients also did not want other people to know that they were taken to a hospice.

In this study, participants indicated that they experienced the care rendered by the hospice as much better than that offered by hospitals. The study participants were much more positive about their communication with hospice staff than their relations with hospital staff, and were generally satisfied with their involvement in decision-making while the patient was receiving hospice care. Participants observed the sympathy and empathy displayed by hospice personnel. Hospital service providers often viewed patients as diseases or objects rather than persons with unique human characteristics and different cultural values and expectations. This left patients and their families with the impression that hospital personnel lacked empathy (Char 2003:380).

Gwyther and Rawlinson (2007:559) stated that the behaviour of hospital staff could be attributed to a shortage of staff caused by, among other things, the so-called 'brain drain' coupled with an increased number of patients, especially patients suffering from AIDS. Quality of care in these facilities was often compromised. Rendering physical care received priority while the emotional care needed by AIDS patients was neglected. Sullivan (2007:79) argued that terminally ill patients expected adequate support and care.

A comparison of the quality of care offered by hospitals and hospices by Addington-Hall and O'Callaghan (2009:190) revealed underlying differences in the needs of patients (and their families) in the two settings, and differences in how these needs were

addressed. Concerning the emotional needs of terminally ill patients, hospice care proved to be the better provider.

The benefits of hospice care observed by participants made them content and less anxious about what other people would say of their loved one in hospice care. According to a study by Twycross (2007:9), the nature of palliative care rendered in home-based and hospice settings lessened the psychological symptoms of patients and improved their physical condition, thereby decreasing opportunistic infections.

A mother of an AIDS patient, in a study by Boyle, Bunting, Hodnicki and Ferrell (2001:197), said the way her child was treated and made whole again by a hospice made her wish that all AIDS patients could come into contact with a hospice at one stage or another. This mother observed the benefits of hospice care. The participants in this study suggested the use of the media to convey the good aspects of hospice care.

With reference to AIDS in the household, Johnson *et al.* (2002:206) stated that women who were sole caregivers were mainly stressed by activities related to mobility and daily living. Hospices alleviated their burden and, like many people who experienced and acknowledged help, they became ambassadors for this form of care. People learned about hospice care through these women.

By introducing palliative care to the community, hospices offered hope to patients and families. They brought relief to family members affected by AIDS by lessening their burden of care (Earl 2005:58). According to Boyle *et al.* (2001:196), as the condition of AIDS-infected adult children worsened and they experienced episodes of serious illness and debility, mothers caring for their adult children became more involved in their children's activities of daily living, including personal hygiene and nutrition. This put much strain on these caregivers. Their lives came to a halt, as caring took up most of their time. It took them a long time to seek help, but the hospice option changed their lives by relieving them of their burden of care.

Strydom and Wessels (2006:4) maintained that stress among caregivers in the field of AIDS manifested itself in a wide range of signs and symptoms: psychological, behavioural and physical. Caring for terminally ill patients caused even more stress. Placing the terminally ill person in either a hospital or hospice alleviated the stress symptoms of caregivers and helped them to regain a degree of normality (Strydom & Wessels 2006:4).

Conclusions

The participants in this study had mixed feelings about hospice care. Some supported the idea and expressed their belief that hospice care was necessary as it brought relief to families who were unable to care for their loved ones at home owing to circumstances such as work commitments. However, some participants felt strongly that hospice care was acultural and foreign to the Batswana way of doing things. Communities still clung to the cultural belief that hospice care was meant for other population groups. Their perception was that hospice care was something new and a result of the new government promoting Western ideas.

Participants who were positive mentioned the benefits of hospice care, namely, improvement in the condition of patients, the care patients received while their families were at work, and family members being able to work while their loved ones were receiving safe care. They expressed their willingness to advocate hospice caregiving, stating that hospices were the better care option. The need was identified to make hospice care and its benefits known to all in the community, and participants were willing to play a role in changing people's mindsets regarding hospice care. They maintained that both patients and families should enjoy the benefits of this care option.

Those against hospice care said hospices were unable to address issues of culture, religion and spirituality of African communities, and mistrusted hospice care as a Western-care method. This study concluded that, although patients and their families were initially uncomfortable with hospice care, they learnt to accept this care option because of the benefits it offered.

Recommendations

The study findings showed that participants regarded culture as an integral part of rendering care. For hospice care to be acceptable to the Batswana, the issue of cultural safety has to be addressed by attending to the following:

- Adaptation of cultural issues to the hospice model. The significant others such as neighbours, the extended family, and the community should be educated to understand the value of hospice care. The community should know the benefits of hospice care for the community, including the benefits of services rendered to AIDS patients.
- Hospices should be introduced as institutions that deliver services to all terminally ill patients, not only AIDS patients, and should integrate patients to avoid stigmatisation especially that of AIDS patients.
- Community members should also be taught to respect the decisions of families, including the decision to opt for hospice care. In order to minimise the stigma and mistrust attached to hospice care, the community should be taught that hospices are not a form of punishment but a combination of services aimed at improving the health status of the terminally ill patient.
- An option must be provided to accommodate those that are feeling strongly against hospices. For example, training must be provided for caregivers and community-based caregivers to be able to provide better care at home.
- Counselling of patients and their families at the hospice should be encouraged and enhanced, as it has shown to improve both the physical and emotional well-being of patients and families.

Summary

The study raised important information in terms of the planning of health care. The culture of the individuals must be taken into consideration to enable healthcare workers to assess, plan and

implement cultural congruent care. Hospice care remains a choice to the clients whose families are working. There is a need to educate the community on the benefits of hospice care.

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