

Nurses experiences in palliative care of terminally-ill HIV patients in a level 1 district hospital

Authors:

Nokwanda E. Bam¹
Joanne R. Naidoo¹

Affiliations:

¹School of Nursing and Public Health, University of KwaZulu-Natal, South Africa

Correspondence to:

Joanne Naidoo

Email:

naidoojr@ukzn.ac.za

Postal address:

Discipline of Nursing, School of Nursing and Public Health, Howard College Campus, University of KwaZulu-Natal, Durban 4000, South Africa

Dates:

Received: 17 Oct. 2013

Accepted: 22 May 2014

Published: 30 July 2014

How to cite this article:

Bam, N.E. & Naidoo, J.R., 2014, 'Nurses experiences in palliative care of terminally-ill HIV patients in a level 1 district hospital,' *Curationis* 37(1), Art. #1238, 9 page. <http://dx.doi.org/10.4102/curationis.v37i1.1238>

Copyright:

© 2014. The Authors.
Licensee: AOSIS
OpenJournals. This work is licensed under the Creative Commons Attribution License.

Read online:

Scan this QR code with your smart phone or mobile device to read online.

Background: Whilst the discourse of palliative care in HIV management is largely documented and regarded as being an essential component, various authors have further argued that within the context of HIV care in sub-Saharan Africa, palliative care and exploration of the dimensions thereof is largely lacking. This article presents the lived experiences of nurses involved in palliative care, thus providing the perspective of nurses and the multi-faceted dimensions of the nature of caring inherent.

Objectives: This study explored the respondents' understanding of the concepts 'caring' and 'terminal patient' and described the experiences of nurses caring for terminally-ill patients with HIV and how these experiences influence the nature of care rendered.

Methods: Qualitative research using Husserl's approach of phenomenology design underpinned the study and Giorgi's steps of analysis were used to make meaning of the data.

Results: The concept 'caring' was experienced by the nurses as transforming the patients' quality of life through supportive care and hope for life. Palliative care made the nurses conscious of their own mortality, enabling them to be more sensitive, compassionate and dedicated to caring for their patients. The findings described the social networking that enabled nurses to collaborate with colleagues in the interdisciplinary teams and shared knowledge, skills and support within the palliative care team in order to optimise patient outcomes.

Conclusion: Nurses with prolonged involvement in caring for terminally-ill patients with HIV experienced helplessness and emotional stress. Recommendations based on the results are that training in psychological and holistic care of the patient, professional counselling and stress management services are needed to support the nurse in this context.

Introduction

Hospital-based HIV palliative care has been the subject of very few research studies (Tapsfield & Jane Bates 2011). Further to this, the Ethics Committee of the University of KwaZulu Natal, after their review of literature related to this area, approved the study which is the basis of this article.

Whilst the discourse of HIV management and palliative care is widely documented (Cullinan 2006; Demmer 2006; Mabude *et al.* 2008), empirical evidence has also illuminated the need for further research into unpacking the intricate nature of palliative management from the caregiver's perspective (Orner 2006; Singh *et al.* 2011). The HIV pandemic has been attributed to causing nurses to feel overwhelmed by the high number of terminally-ill patients they care for who, because of the nature of their compromised illness, require more specialised care than other patients, thus exacerbating the burden on the nurse (Cullinan 2006; Demmer 2006). The nurses' situation is compounded by their contextual issues which include unmanageable workloads, managerial inadequacies and the existing 'paradigm of inequity' between the public and private health sectors (National Labour and Economic Development Institute 2006).

South African public hospitals are heavily challenged (South African National AIDS Council 2011). Over 80% of the country's population have no medical aid cover and are forced to seek treatment in government clinics and hospitals (South Africa 2009). The National Department of Health's 10-point plan strategy (Department of Health 2010) estimated the costs of uninsured people in the public sector at R85 billion as opposed to R113 billion's worth of insured South Africans in the private sector.

Of all the HIV-related deaths in South Africa, KwaZulu-Natal is ranked as having the highest rate, at 14.2%, followed by the Northern Cape (8.3%) and the Eastern Cape at 5.3% (Statistics South Africa 2010). In 2008, a slight decline in HIV-related deaths occurred, particularly in the age group of 15–24 years. This drop accounts for 3.3% of deaths. HIV is ranked fourth amongst the 10 leading causes of natural deaths in the same age group (Statistics South Africa 2013).

The in-house statistics of the hospital in which the study was conducted showed that in 2010, between January and March, there was a progressive increase in the number of people dying of HIV-related illness – an average of 7.1% of the deaths per month. In 2011, the monthly mortality rate of people dying of HIV-related illness increased progressively from 4% in October, to 11% and, finally, 13% in December (Department of Health 2012).

The escalating number of deaths was one of the factors that motivated the researcher to explore the lived experiences of nurses whilst nursing patients with terminal HIV-related illness, in order to understand the phenomenon from the nurses' perspective. Furthermore, the literature review showed very few studies conducted in the palliative care of people suffering from HIV-related illness or disease in sub-Saharan Africa; most studies were Euro-centric within oncology settings.

Problem statement

Research findings, such as those of De Villiers and Ndou (2008), have shown that negative emotions lead to unethical behaviour on the part of the nurses and their inability to create the therapeutic relationships of caring, mutual respect and trust necessary for the protection of the legal and ethical rights of HIV patients. The public has high expectations of nurses, expecting them to provide quality care for patients at all times, regardless of their illness (US Agency for International Development 2009). This study was designed to explore and describe the experiences of nurses caring for patients with terminal HIV-related illness and how these experiences impact on the lives of operational nurses on a daily basis in the context of nursing in palliative settings.

Significance of study

Palliative care is a fundamental aspect of HIV management, despite the increasing availability of antiretroviral treatment as part of the package of care for patients with terminal HIV-related illness. In South Africa, this challenge is exacerbated by the increasing numbers of very ill and dying HIV patients who tend to suffer from complications of the disease and need more specialised care than most other patients (Mngadi 2006). The findings of the study may assist nurse managers and nurse educators with regard to the development and incorporation of educational programmes in their policies and curricula that teach effective coping strategies aimed at minimising 'death anxiety' amongst nurses. The findings may also contribute to evidence-based clinical practice on service delivery approaches such as strategic planning for individualised user-friendly palliative care needs in order to improve patients' quality of life and to identify potential areas for further research regarding caring for patients with terminal HIV-related illness or disease. The study may also improve access to palliative care services in all settings of care delivery and enhance support for HIV programmes, particularly in South Africa where little research in palliative care settings has been conducted.

Aims of the study

The aim of the study was to explore and describe the lived experiences of nurses caring for patients with terminal HIV-related illness in selected wards of a level one district hospital in KwaZulu-Natal.

Research objectives

The objectives of the research were:

- To explore the nurses' understanding of the concepts of 'caring' and 'terminal patient'.
- To explore the lived experiences of nurses caring for patients living with terminal HIV-related illness.
- To explore how the nurses' experiences influence the care they provide to terminal patients with HIV-related illness.

Research questions

The research questions were:

- What is the nurses' understanding of the terms 'caring' and 'terminal patients'?
- What are the nurses' perceptions of their experiences in caring for patients living with terminal HIV-related illness.
- How do the nurses' experiences influence the care they give to terminal patients with HIV-related illness?

Definition of key concepts

Caring is an abstract concept that affirms life rather than death and refers to managing the pain and symptoms of patients who have terminal HIV-related illness or disease in order to maintain their quality of life in their continuum of care whilst in palliative wards.

Lived experience relates to what the nurses do, see and feel; and the unique problems they encounter whilst caring for patients with terminal HIV-related illness.

Level 1 district hospital is a hospital registered to deliver prescribed district services from recognised primary healthcare clinics for further management in order to improve the local healthcare needs of patients, but which transfers patients with complications to level 2 hospitals.

Clinical nurses are registered nurses, enrolled nurses and enrolled nursing assistants who care for patients with HIV-related illness or disease in palliative care wards. Their performance is based on knowledge and application of biological, physical and social sciences on completion of a course of training at an approved school of professional nursing.

Palliative care is the provision of total care by the operational nurses, involving the psychosocial, physical and spiritual well-being of adult patients suffering from HIV-related illness and including support of his or her family, from the time of diagnosis until the death and bereavement stages.

Terminal patient or *terminal illness* refers to patients with HIV-related disease, at an advanced or progressive stage. Although the general prognosis is poor as there is currently no cure for the disease and because inadequate treatment may lead to death, some patients recover 'miraculously' and live for a long time thereafter.

Research method and design

Design

Qualitative methodology, using the Husserlian phenomenology (Laverly 2003), was used with an observational (specifically, the field notes), exploratory and descriptive design to collect in-depth information on the lived experiences of the nurses. The nature of this approach allowed the researcher to be absorbed actively in the subject of the study and to gain an in-depth understanding through the detailed descriptions and explanations provided by the nurses.

Data collection method

The field work was conducted during August 2010 and September 2010. The information document on the study was explained to the participating nurses and consent was signed. Individual appointments were arranged with each participant for the interviews at times and in locations chosen by them. The interview schedule consisted of the three research questions in English and some probes to facilitate discussions with the nurses. The information obtained from the participants was recorded using the tape and also transcribed manually by the researcher who subsequently checked the information with the participants to promote objectivity. Interviews took 45 to 60 minutes. Field notes were taken during each interview.

Data analysis

Data analysis was based on Giorgi's five steps (Giorgi 1985) which involved: (1) getting the general sense of the whole statement; (2) re-reading the text for the purpose of delineating meaning units focusing on the phenomenon being studied; (3) relating the meaning of the units to each other to gain a sense of the whole; (4) transforming everyday expressions into psychological language; and, finally, (5) synthesising the transformed meaning units into a consistent statement of structure.

Context of the study

This study was conducted in a level 1 district semi-private, 200-bed hospital (approximately 60% state-subsidised and 40% donor-funded), situated in the eThekweni District on the outskirts of Durban, KwaZulu-Natal and serving over a million people. The hospital provides level one generalist services to in-patients, with medical, surgical, obstetric and theatre services (for minor operations and caesarean sections), outpatient care for adults and paediatric care. The study population included all nurses working in the palliative care wards of the hospital: professional nurses, enrolled nurses and enrolled nursing assistants. In general, around

30 nurses work in these wards. Permanent employees work on a permanent basis in palliative wards whereas fixed-term employees are rotated as operational needs arise. The palliative care wards comprise 44 beds, of which two wards of 18 beds are for men and three wards of 26 beds for women. Apart from a few other medical conditions, such as hypertension or diabetes mellitus, the majority of patients diagnosed with HIV, both those who are classified as being at stage 3 AIDS (and are thus critically ill on antiretrovirals) as well as those who are not yet on treatment, are admitted to these wards.

A purposive sample of 10 operational nurses was selected to participate in this study. An inclusion criterion of nurses with a minimum of one year caring for AIDS patients and who were willing to participate was used in order to ensure that all the participants had experienced the matters under study and were willing to share their lived experiences.

Results

The demographic characteristics of the sampled participants varied: the mean age of the participants was 34.8 years (range 23–62 years) and the mean number of years' experience in caring for patients with AIDS was 6.4 years (range 1–22 years). Table 1 provides a description of the participants.

The study identified the lived experiences of the nurses in two categories, along with their associated themes and subthemes. The two categories based on the research questions were: (1) conceptualisation of the core terms of caring and terminal illness; and (2) care experiences in the context of HIV-related illness.

TABLE 1: Description of the participants.

Participants	Category	Age	Years of experience in caring for patients with AIDS	Background information
Participant 1	ENA	23	1	Black female, Sotho speaking, Catholic
Participant 2	ENA	26	1	Black female, SiSwati speaking, Catholic
Participant 3	EN	24	2	Black female, Zulu speaking, Christian
Participant 4	EN	24	2	Black female, Zulu speaking, Catholic
Participant 5	EN	30	3	Black female, Sotho speaking, Christian
Participant 6	RN	34	4	Black female, Zulu speaking, Catholic
Participant 7	RN	36	7	Black female, Zulu speaking, Catholic
Participant 8	RN	27	2	Black male, Zulu speaking, Christian
Participant 9	RN	62	20	White female, English speaking, Christian
Participant 10	RN	62	22	Black female, Xhosa speaking, Christian

ENA, enrolled nurse assistant; EN, enrolled nurse; RN, registered nurse.

Conceptualising caring

The participant nurses described caring as arising from one's background and transforming the lives of people with HIV and AIDS. These characteristics are examined in the following sections.

Caring stems from one's background

Some of the participants expressed that their values regarding caring in, at most times, the overburdened environment of palliative care in the context of HIV, had been shaped by their family members. For example, some nurses had previous exposure to episodes of caring for family members who had been ill and in need of palliative care. Some also explained that they had learned about caring from family members who themselves were nurses and had displayed values of compassion, empathy and caring and whose example had shaped their own definition of what caring entails. The selected excerpts presented below highlight this further:

'My own background helped me a lot. I come from a caring family and the marvellous role models I had when I was on training. They were totally professional people and they displayed compassion and dedication.' (Participant 4, Female, 24)

'Caring for me started from home with my mother who was sick in 2003. Because I helped her it has been easier to help someone who is not your relative.' (Participant 2, Female, 26)

Caring enhances patient lives

The results showed that the nurses experienced positive feelings, such as joy, in enhancing the lives of their patients as they helped them to manage the disease:

'For me I get joy when I help or care for someone and I notice improvement, that the patients manage to do something for themselves.' (Participant 9, Female, 62)

'As a nurse, I feel great when a patient is discharged home and after diagnosis with HIV/AIDS, I give them hope through adherence to treatment.' (Participant 3, Female, 24)

Conceptualising terminal illness

The study revealed that terminal illness was conceptualised by the participants as having the aspects of requiring long-term care and raising consciousness regarding HIV. The cognitive and practical meanings of these aspects reflect how nurses perceive their role in preserving the quality of life of patients with terminal HIV-related illness.

Terminal illness requires long-term care

Recognising the impact of antiretroviral drugs, which significantly delay the progression of HIV to AIDS, the participants affirmed that people living with HIV can live relatively normal lives, particularly in cases where early access to treatment and adherence thereto is fostered:

'All the patients with terminal diseases have incurable diseases, e.g. DM [*diabetes mellitus*], HPT [*hypertension*], CVA [*cerebrovascular accident/stroke*], HIV/AIDS. All such patients need special care and can be taken care of at home or in hospital. At times they are independent enough for self-care in their

own communities e.g. IDDM [*insulin-dependent diabetes mellitus*] patients.' (Participant 6, Female, 34)

'Terminal patients may have a disease to carry for the rest of their lives that has no cure. This does not mean that they are dying. They may live for a long time. Okay, only those with HIV/AIDS who are taking antiretroviral drugs.' (Participant 7, Female, 36)

Terminal illness raises consciousness regarding HIV

Responding to the reality of death faced by terminal patients with AIDS, the participants were confronted with the reality of their own mortality as some of them were also infected with HIV. With HIV reaching pandemic proportions and their dealing with suffering and death on a daily basis, the participants realised that they, too, might suffer in such a way in the future and would appreciate kindness and care:

'Caring for terminal patient helps me, because it gives me the awareness that, one day, I may be in their state as well, so this awareness, helps me to care for others more, knowing that I may be there one day.' (Participant 1, Female, 23)

'At times I think about death, I ask myself, if it were me, what would I do? Each time, in the evening, I reflect on this question. Sometimes, I think I will be able to do this and that but, huh, you don't know in reality. I do what I would like done to me. So I care for my patients so they can feel cared for and loved. Eye for an eye, if I do good, somebody will do good for me one day.' (Participant 6, Female, 34)

'We find that some nurses carry the pain alone, as they themselves grapple with their own effects of being infected with the virus. We wish to help them too, but we do not know how. Maybe someday, we will be able to help our own suffering colleagues through research.' (Participant 10, Female, 62)

Experiences of caring in the context of palliative care

From the data analysis, three themes emerged as being compelling forces that influenced the nurses' actions, behaviours and opinions as participants described their experiences of taking care of their patients. The themes were conceptualised as: the social networking system; factors hindering provision of quality care for terminally-ill patients; and mechanisms for adjusting to terminal care.

The social networking system

Being aware that the nature of caring for terminally-ill patients requires the interventions of a variety of health practitioners, the nurses explained that their inter-dependent roles resulted in a state of affinity with other members of staff. This, in turn, developed into collegial relationships and wider social networks. In the context of providing palliative care and managing their care-giving roles efficiently, participants admitted that, apart from their intrinsic values of love and prayer, they drew upon the support of their colleagues and thus developed friendship networks.

'We sometimes talk with the staff, among ourselves, sharing experiences of the day, our challenges and the things that made us happy in the day. At times, the ward doctors join us in these friendly gatherings. This helps to ease the tensions we meet in our workplace with humour.' (Participant 3, Female, 24)

'Team work is uplifting; if you ask someone to do something for a patient and the work is shared, you find that the work is easier; and when we share in our diversity in terms of knowledge and skills we learn from one another and are reinforced, too.' (Participant 7, Female, 36)

'Love keeps me going on to give the care I can to the best of my ability and keeps me passionate about my job, to actually want get up and go to my work. This is sustained with prayer, when, I wake up, I always ask God, "give me strength to carry through this day".' (Participant 4, Female, 24)

'Our management need to support our debriefing sessions with formal policy. When they find us sharing, some of us tend to run away for fear of being seen as doing nothing during work hours.' (Participant 9, Female, 62)

Factors that hinder the provision of quality care in the context of palliative care

It emerged that there were multiple barriers that impeded or hindered the nurses' abilities to provide quality palliative care for the terminally-ill patients with AIDS. Subthemes emerged including: the overwhelming effects of AIDS; and HIV being described as 'just another condition'.

The overwhelming effects of AIDS

It became evident that because of the overwhelming nature of the disease, from the psychosocial responses to the chronic illness trajectory, the participants confirmed that they did not always cope effectively in their roles:

'Spiritually, the nurses are overwhelmed and drained; physically too, *ja*, the disease is very demanding in the sense that patients lie for long in bed and we have to give total blanket bath, feeding and listen to complaining visitors.' (Participant 9, Female, 62)

'At times you find that you have problems with admitted as well as discharged patients who have no one or have no money to go home. As a nurse you are exhausted not because of the work but because of the emotional things you carry.' (Participant 3, Female, 24)

'Due to HIV/AIDS, caring now is more holistic than ever. Because you need the multi-disciplinary team to be involved, e.g. the social worker for those patients with social or financial problems; counselors to support for HCT [*HIV Counselling and Testing*] for treatment adherence; physically the patients are demanding, in the sense that they lie for too long in bed.' (Participant 1, Female, 23)

Despite negative experiences, the study showed that the participants were imbued with the goal of achieving the best quality of care for their patients. During the interviews it became clear that most did all they could to help their patients, to give them a better quality of life by not only caring for them but also by educating them about HIV and AIDS so as to assist them in dealing with the disease:

'It's painful and mind-blowing for me. Sometimes I ask God, with a sense of guilt, "why", especially, if someone of my age dies, I often feel like telling everybody, that AIDS kills, so that they can be aware that people are still dying of AIDS. I wish to spend more time but due to shortage of staff we are restricted from doing more.' (Participant 1, Female, 23)

'... at the end of your nursing experience, you find that you need counselling yourself. We sometimes share with my staff, that it would be very helpful if there would be a trained person in psychology or spirituality for, sorely supporting the staff, so that we can cope with the situation because we are having a lot of experiences that are draining us. Sharing experiences of the day allows for psychological healing.' (Participant 5, Female, 30)

HIV described as 'just another condition'

Because people with AIDS have opportunistic infections, such as tuberculosis and pneumonia, the nurses explained that these infections were so common amongst the terminally-ill patients they cared for that they perceived them as being synonymous with HIV and AIDS. Furthermore, because most of the cases they were dealing with on a daily basis were HIV-related, the participants felt that caring for terminal patients with AIDS was 'self-limiting and monotonous' as they did not have the opportunity to learn about new diseases and current treatments and procedures. As a result, they felt that their academic progress was restricted because of the lack of diversity in the nursing care activities rendered to their patients with HIV and AIDS:

'As nurses on training, it is really, a challenge. Because the cases you care for are all categorised under the same conditions HIV/AIDS; this is limiting in the sense that you do not get to see other conditions, as they are mostly, having HIV/AIDS as the underlying cause e.g. cases for TB, pneumonia. You want to see different conditions, in order to be exposed to learning. Basically, in the clinical practice, it's like you are dealing with HIV/AIDS and TB only.' (Participant 2, Female, 26)

'Caring for HIV/AIDS patients is not stimulating. Because we see the same diseases and we always give the same treatment as they [*patients*] are mostly, having HIV/AIDS, it is very rare to find different diseases.' (Participant 5, Female, 30)

Mechanisms of adjusting whilst caring for terminally-ill patients with AIDS

Many nurses resorted to accepting HIV-related deaths as a reality of life and palliative care training as a way of coping within palliative wards.

Accepting death as a reality of life

The participants stated that the clinical conditions of their patients ultimately worsen and the awareness of death becomes a prominent feature in their lives, forcing them to change their goals and focus on specific end-of-life goals:

'We basically need to adapt to the reality of the situation of HIV/AIDS in order to help the patients. The disease itself is reality and nothing can be changed as such. It's me who has to change and accept that patients with HIV/AIDS eventually have to die.' (Participant 4, Female, 24)

Others identified negative attitudes amongst some of the younger nurses, whose behaviour at times demonstrated an uncaring attitude:

'The experience of death does not touch some younger nurses at all. Even when they are bringing the corpse to the mortuary, they talk something we never did. Exposure to the HIV/AIDS disease

as well, makes some hard. They seem to be getting used to death such that it's perceived as a routine.' (Participant 1, Female, 23)

Training in palliative care

Recognising the multiple symptoms and complex drugs used by some patients in palliative wards, training was identified as being imperative with regard to the provision of quality palliative care services to patients with HIV-related illness:

'All patients deserve some basic care. A lot of patients we see are using many drugs to treat the varied symptoms they present with. Training in psychospiritual care and palliative care is critical and would equip us to care for them better, we would cope better too.' (Participant 2, Female, 26)

'My training and long experience in these wards is an enabler for me. I have more understanding of pain and symptom control than the younger nurses with little exposure in these wards.' (Participant 5, Female, 30)

Ethical considerations

Written ethical approval was obtained from the University of KwaZulu-Natal Ethical Committee, on 14 May 2010 (reference HSS/0234/2010H). Permission from the hospital management was obtained so as to ensure that the rights of the participants were protected. This study did not have any direct risk for the participants, as participation was voluntary and was based on experiences regarding palliative care. There was no reported or observed psychological distress noted amongst the participants. Should this have occurred, the researcher had arranged a psychologist from the institution for immediate counselling and support.

Informed consent

The information document was given to all selected participants and the researcher carefully explained the nature of the research. Information regarding their right to refuse to participate or to withdraw from the study without repercussion was reinforced in the document. A day after the information sheet was given out, informed consent was sought from willing participants.

Data protection

Before and during data analysis, the transcripts were kept in a locked cupboard to which only the researcher had access. Data were captured on a computer secured with a password known only to the researcher. Audio tapes were kept in locked cupboards which could only be accessed by the researcher. After a period of five years, the data will be deleted permanently and the hard copies kept by the supervisor; and the audio tapes will be destroyed by burning.

Trustworthiness

Trustworthiness of the study was achieved through methods suggested by Lincoln and Guba (1985), by using the principles of sound credibility. This ensures that the findings of the study can be accepted as true.

Credibility: On completion of each interview, the researcher gave the participants a short summary to check that their ideas had been captured properly and to provide an opportunity for correction or clarity where necessary. In addition, credibility was ensured through audio-recorded interviews in order to ensure that the researcher did not misinterpret the participants' own wording. Field notes were written immediately following each interview to ensure that no meaningful information was overlooked.

Confirmability of the study was established through several techniques. The researcher kept in writing her ideas and experiences (bracketing) as an awareness of personal opinions and beliefs on the care of patients dying from HIV-related illness so that they did not influence the study. An audit trail was established by clarifying the steps taken in the research process in order to ensure that the study adhered to the philosophical underpinnings.

Transferability indicates that the material of the study is described in detail so as to enable readers to evaluate the contexts where the conclusions of the research could be relevant. In addition, transferability was achieved through rich description, whereby the research process, the characteristics of the participants and the study context are supplied for readers to determine the extent to which the circumstances are similar to their own context.

Discussion

Conceptualising caring

Caring stems from one's background

The nature of work the nurses engage with on a daily basis is prescribed morally by their profession (Zuzelo 2007). They are expected to comply with the wishes of the patients and their families, even though these values may not necessarily be in agreement with their own views. Indoctrination or some moral education (whether taught or modelled) is necessary for the personal development of the nurses so that, as members of the professional body of nursing, appropriate behaviour is consistently evident in meeting the unique needs of patients in palliative care (Tan 2004). The study revealed that the nurses' socialisation background had inculcated values and norms that were applicable to the needs of the terminal patients and, in this way, they did 'fit into their moral profession as carers' (Zuzelo 2007), contributing to the total well-being of their patients by meeting the expected cultural and emotional values of showing respect to their elders and caring for people with HIV and AIDS as if they were relatives.

Caring enhances patient lives

Supportive leadership and personal recognition recommend supportive strategies which advocate for individualised consideration by encouraging behaviours that facilitate other people's needs and preferences such as showing concern for their welfare, thus creating friendly, supportive and therapeutic environments (Rafferty & Griffin 2004). The

participants used supportive measures to re-establish a sense of hope and dignity in the patients who were in despair and refusing to take treatment after having been diagnosed with HIV. Patients' lives were transformed by the care shown by the nurses who were in turn emotionally reinforced in their caring roles.

Conceptualising terminal illness

Terminal illness requires long-term care

With the emergence of effective antiretroviral therapy and palliative medicine, there has been much improvement in HIV management. The control of viral replication has led to a reduction in the premature death of patients with AIDS (South African National AIDS Council 2011). Furthermore, it is a proven fact that HIV-positive patients who have access to treatment and who maintain a 90% adherence rate, have improved their quality and duration of life as compared with one or two decades ago (Masur 2009). Many of the patients who complied with treatment recovered, showing that the effects of the disease had been transformed from terminal to chronic.

Terminal illness raises consciousness regarding HIV

A study conducted by van Rooyen, Williams and Ricks (2009) on lived experiences of caregivers working with patients dying from HIV-related illness revealed a myriad of emotions being experienced by the participants. Most perceived the death of dying patients more positively, as an experience that facilitated mental and spiritual growth. A few found it difficult to accept the death of dying patients and perceived bonding with them as being a threat to their psychosocial well-being, resulting in feeling drained and experiencing burnout. The study participants generally concurred with the former view, taking part in their patients' deaths and listening empathetically to them so as to care as they would want to be cared for.

Experiences of caring in the context of palliative care

The social networking system

Munro and Edward (2008:123) arguing for the needs of the patients, adding that 'the nurses need to have an understanding of intimate interpersonal relationships in nursing' so that they can maintain therapeutic relationships by taking into account the individual needs of not only the patients, but also their loved ones.

Within the palliative care teams and the interdisciplinary teams, the participants created mutual supportive relationships and used humour, love and prayer to contribute positively to the challenges of caring for HIV patients in order to achieve quality patient outcomes in a friendly palliative care context. However, the nurses need management support so that their informal debriefing sessions are formulated into a policy to enable them to sustain the formalised policy consistently without fear of being seen as not doing their actual duties.

Factors that hinder the provision of quality care in the context of palliative care

The overwhelming effects of AIDS

It is generally known that South Africa is a leading country in sub-Saharan Africa in the provision of palliative care (Kell & Walley 2009). However, it became evident that the demands of caring overwhelmed the nurses and hindered the delivery of quality palliative care to HIV patients.

Despite the physical and psychological effects experienced by the nurses in caring for terminal patients, they remained determined, desiring to do more 'to go the extra mile' for their patients in order to achieve quality palliative care delivery.

HIV described as 'just another condition'

According to Masur (2009), it is generally known that most patients admitted to patient-care units have HIV or need HIV-related treatment, thus clinicians need to consider HIV infection as being one of the major factors in both their short- and long-term assessments of patients. This empirical evidence supports the participants' perceptions in the current study that tuberculosis and pneumonia were almost synonymous with HIV and AIDS and assists in the understanding of their personal challenges in rendering quality nursing care to patients with HIV. In this study, the nurses were 'AIDS fatigued', as they perceived patients suffering from the disease as being an impediment to their academic development and stimulation. In other words, AIDS was no longer an interesting agenda for their learning.

Mechanisms of adjusting whilst caring for terminally-ill patients with AIDS

Accepting death as a reality of life

Although antiretroviral treatment has shown a successful transition of AIDS from a terminal to a chronic disease state, Mngadi (2006) argues that cost issues hinder the progress of successful outcomes in palliative care, as antiretroviral treatment is neither free nor available to 90% of people living with HIV and AIDS in sub-Saharan Africa. The result is that millions of people are living with the disease and are subject to increasing impairment of the immune system which is exacerbated by opportunistic infections and frequently results in premature death. Consequently, the nurses in the current study were confronted with a situation that was beyond their control, reviving the lives of immunosuppressed patients admitted to palliative care wards. Death occurred on a daily basis and was thus experienced as a reality of life to which they had to adjust and which had to be faced head on in order to allow them to continue caring for patients with AIDS.

Training in palliative care

To improve access to antiretroviral treatment, skills development process is necessary and should include the development of standardised clinical guidelines, simplified recording and reporting systems that assist doctors and nurses in their clinical interventions (Pillay 2010). It is evident

that training tailored for palliative care services enhanced the professional and clinical expertise of the nurses. They were in a better position to understand patients' changing conditions and to render appropriate treatment. In addition, the nurses with prolonged experience in palliative care wards coped better than those who had little exposure as they still had to adapt to patient dynamics in terms of diagnosis and the treatment needs thereof.

Limitations of the study

The study was qualitative research amongst nurses working in a district level 1 hospital palliative ward for patients who had terminal HIV-related illness and does not claim to be a quantitative representation of all nurses in KZN district healthcare.

Recommendations

The following recommendations from the study findings could help to improve the working conditions of nurses in palliative care wards whilst providing care for terminally-ill HIV patients.

Clinical recommendations

It is recommended that institutions review their palliative care work load and attend to staff shortages. The nurses in this study were overwhelmed with the intensive and specialised nature of nursing care which included demanding tasks such as performing a total blanket bath, feeding and giving of medication to very frail patients. The nurses reported a yearning for a break from the routine tasks such as those noted, as well as a chance to engage in more psychosocial interactions with the patients such as listening to the patients' problems, which they did not always have time for during the course of the comprehensive routine care regime. This interaction would assist them in providing holistic and humane care to their palliative care patients.

Educational and professional recommendations

Nurses felt that caring for HIV patients prevented their academic and professional growth and development. Amongst the chronic patients they cared for were those who had opportunistic infections such as HIV-related tuberculosis and pneumonia, thus the nurses had limited exposure to new learning. In addition, the demographic data showed that the age groups of the nurses working in palliative care wards were as follows: five were in their 20s, three in their 30s and two were over 60 years of age; and their experience varied from between three years for eight of them and 20-plus years for the other two. Only two of the nurses had formal training in palliative care. The nurses with prolonged exposure to palliative care wards showed more support and care for dying patients than with those with fewer years of experience; therefore, additional training and experience in psychological and spiritual counselling are crucial when allocating nurses to palliative care wards to assist both patients and their colleagues with regard to palliative care.

Managerial and policy recommendations

Social networks between the multidisciplinary teams of doctors and nurses added mutual support humour and enhanced the coping mechanisms of nurses caring for dying HIV patients. In order to achieve effective leadership at all levels, from the basic categories of nurses to the policy-formulating professionals, it is vital to provide debriefing sessions whereby the palliative teams share their experiences whilst learning from one another so as to improve the quality of life for their patients.

Research recommendations

Caring for patients with AIDS conscientised the nurses to the reality of their own mortality, as some of them were themselves infected with HIV. To benefit the nursing profession, studies need to focus on nurses who are infected with HIV in order to find out what their needs are and how their positive status impacts on their care of patients with HIV and AIDS.

Conclusion

During data analysis, the findings of the study emerged as two distinct categories, namely, (1) conceptualisation of the core concepts of caring and terminal illness; and (2) experiences of caring in the context of palliative care.

The conceptualisation of the core concepts influenced the nurses' actions, behaviours and attitudes as they described their experiences with regard to taking care of terminally-ill patients with AIDS. The lived experiences had three main themes: (1) social networking, allowing them to collaborate with colleagues in the interdisciplinary teams and to share knowledge, skills and support within the palliative care team in order to optimise patient outcomes; (2) factors that hinder nurses' abilities to provide quality care for their patients; and (3) the internal and external mechanisms that enable nurses, despite challenges, to provide palliative care. The expressed need for additional training in psychospiritual counselling, as well as an environment that allows for social networking and debriefing sessions amongst colleagues and adequate staffing, will contribute to quality palliative care service delivery for terminally-ill patients.

Acknowledgements

The authors would like to convey gratitude and acknowledgement to the nurses who participated in the study and grateful thanks to the research supervisor, friends, colleagues and management of the hospital for the support and encouragement they provided during the course of the study.

Competing interests

The authors declare that they have no financial or personal relationship(s) which may have inappropriately influenced them in writing this article.

Authors' contributions

N.E.B. (University of KwaZulu-Natal) was the student and primary researcher of this study, who collected and analysed the data for this study. J.R.N. (University of KwaZulu-Natal) was the supervisor of the study and assisted in data analysis of emergent themes.

References

- Cullinan, K., 2006, *Health services in South Africa: a basic introduction*, viewed 29 June 2014, from http://www.health-e.org.za/wp-content/uploads/2013/04/Health_services_briefing_doc.pdf
- De Villiers, L.D. & Ndou, N.D., 2008, 'South African professional nurses' experiences of caring for HIV/AIDS patients', *Africa Journal of Nursing and Midwifery* 10(1), 5–21.
- Demmer, C., 2006, 'Confronting AIDS-related loss and grief: An exploratory study of professional caregivers in KwaZulu-Natal, South Africa', *African Journal of AIDS Research* 5(2), 97–107. <http://dx.doi.org/10.2989/16085900609490370>
- Department of Health, 2010, *National Strategic Plan for South African (2010/11–2012/13)*, Pretoria, South Africa.
- Department of Health, 2012, 'Hospital performance indicators', unpublished document, St Mary's Marianhill Mission Hospital, Pinetown.
- Giorgi, A., 1985, *Phenomenology and Psychological Research*, Dusquesne University Press, Pittsburgh, PA.
- Kell, M.E. & Walley, J.D., 2009, 'Palliative care for HIV in the era of antiretroviral therapy availability: Perspectives of nurses in Lesotho', *BMC Palliative Care* 8(11), viewed 04 January 2012, from <http://www.biomedcentral.com/1472-684X/8/11>
- Laverty, S.M., 2003, 'Hermeneutic phenomenology and phenomenology: A comparison of historical and methodological considerations', *International Journal of Qualitative Methods* 2(3), 21–35.
- Lincoln, Y.S. & Guba, E.G., 1985, *Naturalistic enquiry*, Sage Publications, Inc., Newbury Park, CA.
- Mabude, Z.A., Bekinska, M.E., Ramkissoon, A., Wood, S. & Folsom, M., 2008, 'A national survey of home-based care kits for palliative HIV/AIDS care in South Africa', *AIDS Care* 20(8), 931–937. <http://dx.doi.org/10.1080/09540120701768438>
- Masur, H., 2009, 'Caring for AIDS patients in the ICU: Expanding horizons', *Chest* 135(1), 1–2. <http://dx.doi.org/10.1378/chest.08-2199>
- Mngadi, K., 2006, 'Palliative care in advanced HIV', *South African Pharmaceutical Journal* 73(9), 14–18.
- Munro, I. & Edward, K.L., 2008, 'The lived experiences of gay men caring for others with HIV/AIDS: Resilient coping skills', *International Journal of Nursing Practice* 14(2), 122–128. <http://dx.doi.org/10.1111/j.1440-172X.2008.00675.x>
- National Labour and Economic Development Institute, 2006, 'An investigation into the management of public hospitals in South Africa', unpublished research report commissioned by the Department of Public Service and Administration.
- Orner, P., 2006, 'Psychosocial impacts on caregivers of people living with AIDS', *AIDS Care* 18(3), 236–240. <http://dx.doi.org/10.1080/09540120500456565>
- Pillay, R., 2010, 'The skills gap in hospital management: A comparative analysis of hospital managers in the public and private sectors in South Africa', *Journal of Health Management* 12(1), 1–18. <http://dx.doi.org/10.1177/097206340901200102>
- Rafferty, A.E. & Griffin, M.A., 2004, 'Dimensions of transformational leadership: Conceptual and empirical extensions', *The Leadership Quarterly* 15(3), 329–354. <http://dx.doi.org/10.1016/j.leaqua.2004.02.009>
- Singh, D., Chaudoir, S.R., Escobar, M.C. & Kalichman, S., 2011, 'Stigma, burden, social support, and willingness to care among caregivers of PLWHA in home-based care in South Africa', *AIDS Care* 23(7), 839–845. <http://dx.doi.org/10.1080/09540121.2010.542122>
- South Africa, 2009, *Green paper: National strategic planning*, viewed 28 June 2014, from <http://www.polity.org.za/article/green-paper-national-strategic-planning-september-2009-2009-09-07>
- South African National AIDS Council, 2011, *National Strategic Plan for HIV, STIs and TB 2012–2016*, viewed 28 June 2014, from <http://www.hst.org.za/publications/national-strategic-plan-hiv-stis-and-tb-2012-2016>
- Statistics South Africa, 2010, *Mortality and causes of death in South Africa, 2009: Findings from death notification*, viewed 28 June 2014, from <http://www.statssa.gov.za/publications/P03093/P030932009.pdf>
- Statistics South Africa, 2013, *Mid-year population estimates 2013*, viewed 28 June 2014, from <http://www.statssa.gov.za/publications/P0302/P03022013.pdf>
- Tan, C., 2004, 'Michael Hand, indoctrination and the inculcation of belief', *Journal of Philosophy of Education* 38(2), 257–267. <http://dx.doi.org/10.1111/j.0309-8249.2004.00380.x>
- Tapsfield, J.B. & Jane Bates, M., 2011, 'Hospital based palliative care in sub-Saharan Africa: A six month review from Malawi', *BMC Palliative Care* 10(12), viewed 04 January 2012, from <http://www.biomedcentral.com/1472-684X/10/12>
- US Agency for International Development, 2009, *Palliative care: A continuum of patient-centered care. Technical Issue Brief*, viewed 04 January 2012, from <http://www.usaid.gov>
- Van Rooyen, M., Williams, M. & Ricks, E., 2009, 'Caring for terminal AIDS patients: The experiences of caregivers in a palliative care institution', *Health SA Gesondheid* 14(1), Art. 440, 11 pages.
- World Health Organization, 2011, *Africa project on palliative care*, viewed January 2012, from <http://www.who.int/cancer/palliative/africanproject/en/index.html>
- Zuzelo, P.R., 2007, 'Exploring the moral distress of registered nurses', *Nursing Ethics* 14(3), 344–359. <http://dx.doi.org/10.1177/0969733007075870>