Abstract

The Patients’ Rights Charter (Health Professions Council of South Africa (HPCSA), (2008) stipulates the provision for “special needs in the case of persons living with HIV or AIDS” and palliative care that is both “affordable and effective”. But exactly what palliative support and care is wanted by HIV positive patients is not clear. This study explored the palliative care experiences of Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) patients and their families. Interviews were performed, on patients and family members of other patients who had received palliative care in a small urban palliative care centre. The research question was, “What was your experience of being cared for in the care centre?” Sampling was purposive and continued until saturation was reached (which was after ten interviews). The interviews were recorded and data transcribed verbatim. The data were analysed, identifying themes and sub-themes using a computer programme (Atlas.ti 6.1) and in collaboration with a co-coder. The study concluded that patients want good holistic care. The most important aspects of care named by the patients and their families were compassion, respect, dignity and spiritual support. The care that patients want is holistic, unsophisticated and relational. This kind of care is what is promoted as palliative care by the World Health Organisation.

Keywords: Palliative care, HIV and AIDS, experiences of patients and families.

How to cite this article:

Introduction

Despite the successful role out of Anti-Retrovirals (ARVs) in South Africa, there remains a great need for palliative care for persons facing a life threatening illness such as Human Immunodeficiency Virus (HIV) or Acquired Immune Deficiency Syndrome (AIDS). The problems of facing a life threatening illness are burdensome, complex and varied despite the use of ARVs (Harding et al., 2012). In South Africa HIV prevalence continues to be high at 15.9% and the incidence of HIV/AIDS infection is 29.5% (National Department of Health (NDoH), 2014). It is estimated that more than two million people are on anti-retrovirals (ARV’s) which has greatly decreased AIDS mortality (NDoH, 2014); but there are still a substantial number of persons who die from AIDS related illnesses and complications annually. However, UNAIDS (Opie, 2012) estimate
that only 40-59% of clients eligible for ARV’s in South Africa, receive them. Khan and Sayed (2011) reported that five years after commencement of ARV’s, twenty five percent of patients passed away. In 2012 it was estimated that AIDS mortality was 240,000 (NDoH, 2014). While this shows a decrease from the previous reporting period, there still remains an extremely high death rate and care need.

According to Hospice Palliative Care Association of South Africa (HPCASA) 2013 annual report, 82,681 patients were cared for of which 38% were new patients. Fifty-nine percent of the 82,681 were diagnosed with HIV. Comparing this with their 2003 report which stated 24,613 patients had been cared for; a 33.5% increase is evident. There is an increased need for palliative care in South Africa. Frequently the palliative care needs of the patient are unmet (Majumdar & Mazaleni, 2010).

Palliative care is fundamentally about bringing comfort to the patient and Doyle (2008) states that “the essence of palliative care is the relief of suffering”. Despite the increasing need for palliative care in South Africa few resources are used to support those in need and little research has been carried out to explore the experiences of persons terminally ill with HIV and AIDS and their families (Harding, 2012). The purpose of this study was to explore and describe the lived experiences of HIV and AIDS patients and their families regarding palliative care in an urban care centre in Buffalo City. This brought about a comprehensive understanding of care wanted by the terminal patient and their family.

Methodology

The research design of this study was qualitative and phenomenological in nature as it dealt with the complexity of the patients’ and families’ lived experiences (Burns & Grove, 2009; Creswell, 1994). It was exploratory, descriptive and contextual; allowing participants to explain their experiences in depth.

Data collection

The researcher (an “insider”) was known to the patients and family members of patients who had been cared for in a care centre in Buffalo City. One-on-one interviews enabled the researcher to “stay close” to participants and gain in-depth insights. This inter-subjectivity enabled the researcher to give vivid expression to the experiences of participants (Husserl, Moran & Gibson, 2012). All the interviews were conducted in English and took place at the care centre. The central question asked of patients was, “What was your experience of being cared for in Dignity House?” and of family members, “How did you experience the care given to your family member in Dignity House?”

After the central question was asked, the researcher listened carefully to the participant’s response and probed deeper. Often reflecting or paraphrasing what
the participant had said brought out further meaning to the actual words used. Stating the observed gestures or repetitions made by the participant elicited further information. Pausing to allow time to think was important. Interviews were recorded and transcribed verbatim, leaving grammar and repetitions unchanged to decrease loss of information and emphases. Interviews were conducted until saturation was reached which occurred after interviewing six patients and four family members of other patients.

The study was conducted at nine bedded palliative care centre (Dignity House) in Buffalo City, Eastern Cape. Dignity House was a department of Sophumelele Clinic Incorporated, a non-governmental organisation which served HIV infected and affected people through health, enterprise development and education programmes. Dignity House was a nurse driven hospice, working in close collaboration with the interdisciplinary team sharing the same philosophy of palliative care. Low-technology care was provided for HIV and AIDS patients in a homely and relaxed atmosphere.

The population were all patients cared for in Dignity House and family members of any patient who had received care there. A purposive sampling technique was used by choosing patients who had been discharged from the care centre and family members of discharged or deceased patients so as to maximise their freedom to share honestly, without fear of any negative treatment. Inclusion criteria were patients who had been previously admitted in the care centre for longer than 3 weeks; or family members of patients who had difficult situations or prognoses or who were no longer available to share their experiences (due to their passing or moving away). Participants needed to be proficient in English (due to the researcher’s inability to conduct interviews in indigenous languages).

Ethical considerations
Ethical clearance was obtained from the University of Fort Hare (UFH/UREC, 19 – REC-270710-028) and ethical standards in research were adhered to (DENOSA). Permission was obtained from the management of the care centre and informed, written consent was obtained from each participant without any coercion.

Confidentiality was ensured by the researcher conducting the interviews herself, as the patients already knew the researcher from being cared for in the care centre and their identity was not revealed to any other person. All information that could link the interview to a particular person was removed by the researcher before the data was shared with the supervisor and co-coder. None of the participants in the study were expected to reveal information or identities that they did not want to share thus respecting their privacy. The use, safekeeping and subsequent destruction of the audio-recording was done in such a way that only the researcher and persons directly related to the study could have access to it.
The principles of fair treatment, beneficence and non-maleficence were implemented by inviting participants to volunteer after the patient was discharged from the care centre ensuring that what was said in the interview could not influence the care they received. Participants were free to withdraw from the project at any time without any negative consequences. Counselling was available to all participants should they need it.

**Trustworthiness**

The researcher ensured trustworthiness of the study by using the model of Lincoln and Guba (1985) and the criteria of Polit, Beck and Hungler (2001). Techniques such as triangulation of data, peer debriefing to identify researcher’s biases, were used to obtain **credibility**.

The researcher also gave a detailed description of how the research was conducted in order to allow **transferability**. **Dependability** was ensured by peer review auditing the processes used by the researcher to determine whether they were acceptable. **Confirmability** was also achieved by an audit of internal agreement between the researcher’s interpretation of data and the actual evidence.

**Data analysis**

A method of open coding was used and the data analyzed according to Tesch’s data analysis method and eight steps of analysis (Creswell, 1994). The researcher and an independent coder analysed the data separately and data were organised into themes and sub-themes.

In order to complete these steps more efficiently and in detail, the computer program *Atlas.ti 6.1* was also used to do automatic coding and refine the analysis. Consensus about the findings was obtained through discussion between the co-coder, the researcher and the supervisor of the study. Themes and sub-themes were then identified in the transcription and the field notes.

**Results and Discussion**

Themes and sub-themes were identified. The first theme with its sub-themes are presented in Table 1 and discussed separately.
Table 1: Summary of themes and sub-themes

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
</tr>
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<tbody>
<tr>
<td>Experienced the care they received as holistic in nature:</td>
<td>The clients expressed that they were cared for as a unique person with a body, soul and spirit:</td>
</tr>
<tr>
<td>Body</td>
<td>• Treated with care and compassion</td>
</tr>
<tr>
<td>Soul</td>
<td>• Treated with respect</td>
</tr>
<tr>
<td>• Experienced encouragement hope and support</td>
<td>• Experienced the right to exercise choices and autonomy</td>
</tr>
<tr>
<td>• Experienced the right to be educated and receive relevant information</td>
<td>• Treated with dignity</td>
</tr>
<tr>
<td>Spirit</td>
<td>• Experienced spiritual support through prayers, counselling and religious meetings</td>
</tr>
</tbody>
</table>

**Experienced the care they received as holistic in nature**

Most of the respondents commented on the care they had received as holistic. One patient spoke about the pain control she had received and summed it up by saying, “*People here have a holistic approach. When you need healing from any disease you need prayers, good care, love and people who understand*”. Palliative care is known to be holistic in nature, providing comfort and not just making patients feel more comfortable (Chochinov, 2006). This means much more than just the technical competence of symptom management. Patients want a holistic approach to end of life care that includes the psychosocial, existential, and spiritual aspects of the patient’s experience.

**Body: Treated with care and compassion**

All the respondents described the care as an important aspect of their experience in Dignity House. Patients mentioned different aspects of care that were important for them. Pain control and good food were reported by many but they all spoke of care as being vital to them. “*The way they treated me was the most important thing*. “*Here you stand in front of me; you are wait in front of me with water. So I can’t even throw [the pills]. Because you want me to be well.*” “*So it was that close, close care that I wanted*”. Chochinov (2007) states compassion is a vital part of palliative care. This can only come about in relation with the patient – as the care giver establishes contact, understands, feels and allows that to shape their approach to care. Care is so much more than the treatment of the illness (Peabody, 1927). Caring is shown by understanding the patient and not just his or her illness. Patients want empathy and closeness from their care givers.
Body: Treated with respect
Dignity and respect are closely related and are general principles of palliative nursing (Ferrell & Coyle, 2005). All the participants in this study reported feeling that they had been treated with dignity and respect. They had had the right to make decisions and their beliefs and cultural practices were acknowledged. Patients desired respect and dignity. This is supported by the following quotes “They don’t discriminate, they treated the other patients the same, whatever background you are from they make you feel at home”. “It was like family, like somebody looking after me at home nicely”. “…treated like a queen”. “Nobody was shouting at me… Nobody was saying, ‘Why do you do this?’ So I was feeling at home”.

Soul: Experienced encouragement, hope and support
When a palliative care patient enters a hospice type system, he or she is most vulnerable, as often this is seen as the last phase before passing away. Encouragement includes recognising small improvements or successes. When the patient’s pain is controlled or they increase in weight; when they manage to swallow their pills or recognise their medication, there is cause for celebration. Often patients who develop an Immune Reconstructive Inflammatory Syndrome (IRIS) become discouraged and think that ARVs are making them sick. One patient told how the nurse had explained about the effects of her very low CD4 count, her IRIS and how that helped her to continue the struggle to take her medication. Others said, “[I received] a good support. It just shows how do they care.” “In that Dignity House people get healed, people get saved. What you did here it is making us want to get better. It’s an encouragement.” Families also felt that they were supported by the nursing staff: “They would encourage and reassure him. That is a very important part of the care”. “But the nurses here are smiling and they give hope every time”. “They motivate and encourage the patients to hold on and to know that they are living with HIV”. Patients seek hope and support and this can be given by helping patients understand their situation. Palliative care offers the hope of comfort and being comforted even in the face of death (Chochinov, 2006).

Soul: Experienced the right to exercise choices and autonomy
Autonomy and choice is highly valued in most societies today. In South Africa, it is a patient’s right to choose one’s health provider and to choose to refuse treatment (HPCSA, 2008). In ethics, personal autonomy and the protection of the vulnerable patient is a key concern (Entwistle, Carter, Criibb & McCaffery, 2010). This is founded on the understanding that we all need to be our own person and shape our own lives. Running our own lives and making our own choices are basic to meaningful living (Horst, 2012). This is particularly true in palliative care, where the patient may need assistance with many daily bodily functions, the choices they can make, are very important to them. Most of the patients made mention of this: “We are asked, ‘What would you like to eat?’
What do you like? And how much?” “I could have any food I wanted and the care was wonderful because I could get up and go to the toilet whenever ... I was not bound by [their routine]”. The nurses stated that patients were usually given one option for each meal and that there were clear limits as to what could be offered to patients both in food and service.

Cassell (2004) suggests that the more an individual’s sense of self and personhood is threatened or undergoes disintegration, the greater his/ her suffering. Often due to the pressure of the work load in the health field, it is difficult for medical staff to respect the patient’s wishes. The dying patient is particularly vulnerable, as they often face many losses and severely limiting disease. Personal autonomy is often integrated with the idea of being a whole person and so conversely, a lack of choice or dependency can be experienced as a threat to personhood itself (Chochinov, 2006). The importance of this individualized autonomy is clearly stated by the participants of this study and can often be achieved by small adjustments in order to offer the patient as many options as possible.

**Soul: Treated with dignity**

Dignity is a general principle of palliative nursing (Ferrell & Coyle, 2005). It can be defined as feeling comfortable, in control and valued. Environment and staff behaviour impact on it. Staff being abrupt, authoritarian or breaching privacy threatens dignity (Baillie, 2009). The more health care providers affirm the patient’s value by seeing them as a person rather than a disease or diagnosis, the more a patient feels treated with dignity. The patient’s own self-perception is also an important factor in the patient feeling dignified (Chochinov, 2007).

In this study, most families implied that they and their family member had been treated with dignity: “... this place is so dignified”. “(The patients) are comfortable and they are warm. They feel at home here”. This was shown to be particularly important for patients in this study where many of them had previously been stigmatised and ill-treated because of their HIV status. One patient spoke of the clothing, “But the nighties that we wear here, not open ... and today you are wearing pink and tomorrow blue ... It made me to feel fresh and comfortable. (It was important) for my health so that maybe I would get quickly recovered and also feel accepted ... maybe they [family] don’t accept me because I was HIV positive ... the stigma of the HIV positive, and also the problem of being accepted by the community... they don’t know what to do with us”. Patients want to be valued and treated with dignity.

**Soul: Experienced the right to be educated and receive all relevant information**

It is agreed that information and education are vital to help palliative care patients make informed choices and plan for the future (Grant, Brown, Leng, Bettega & Murray, 2011; Harding et al., 2012). In this study the nursing staff
fostered a relationship with the patients and their families, evidenced by the following statements by patients: “The way the staff look after you here. They don’t shout at you but they explain things. You see those were the nicest things. The way they chat with you” “...it’s the approach, even they talk with you”

Health education depends on relationship, information and understanding between the parties communicating. As the parties grow to understand one another better, so their communication improves. Part of communication is the feedback and questions that are asked between communicators (de Villiers & Tjale, 2004). The patients and families were not afraid to ask questions about palliative care and their conditions: “If you want to ask something no one is changing” “...I learnt a lot here ...” “You feel free to ask any question” “[the patient] was getting education through the educators - all things about HIV and what is happening with ARV’s”.

One patient had stopped taking her treatment previously because she never understood why she had to continue treatment. Some months the pills had different colours and names and even though she felt much better, the nurses continued to give her more packets of pills to swallow without any explanations. She told how thankful she was for the way she had been taught about HIV and how ARVs function: “...now I even know the names of all my pills and everything”.

The provision of accurate information relieved some of the anxieties and fears people living with HIV experience. Communication allowed them to realize that what they are experiencing is normal and does not signal that something is wrong (Mandla, 2009). The fears of this patient were allayed. “I saw the [staff] accepting me [even] when I’m asking too much questions”. Patients want to be informed, ask questions and have free access to understandable information.

**Spirit: Experienced spiritual support through prayers, counselling and religious meetings**

It is generally accepted that spirituality and religion are very important to palliative care patients (Edwards, Pang, Shiu & Chan, 2010; Harding et al., 2012). Selman et al. (2011) reported 25% of patients in their study did not feel at peace (existential, social, religious and physical). In a study carried out in Dignity House (Phutu, 2011) 80% of patients felt angry with, and had not forgiven, the person(s) who had infected them with HIV. They also reported feeling guilty and not forgiven by God. This would seem to indicate a great need for psychosocial and spiritual care.

Frankl (1985) explored how facing even the most difficult of situations, and having a positive attitude, could bring fulfilment and make meaning in and of itself. Research has shown that many patients not only cope with a diagnosis of
HIV, but grow to the extent that they find their life to be better than before being diagnosed with HIV (Szaflarski et al., 2006). This shows the major importance of spiritual care in the lives of patients living with HIV.

In this study half the family members and all but one patient mentioned some aspect of spiritual care as being important to them. Prayer is the most frequently used spiritual practice (Dijoseph & Cavendish, 2005). “We get prayed for because we are visited by the pastor ... And even the staff, they pray... for and ...with you - meaning that you get looked after spiritually, emotionally and physically”. “[the nurses] could pray with me”. One family member told of her non-religious relative: “Even he was saying that they are praying for us here every day. It was nice.” A patient spoke of how prayer healed her agonising pain, “...I would feel the pain in me going away, I would feel a strength coming to me, whilst I was busy praying...”

Often patients were too ill to leave the care centre, but those who were well enough were invited to attend the nearby church or prayer meetings. This was particularly important to the following two patients: “I was excited every Sunday, I’m going to be with everyone in the church, talking and they just make you comfortable.” “They [staff] gave me good care. Cos I went to prayer meetings on Wednesdays and church on Sundays”. It appears that attending religious meetings helped some patients spiritually and assisted in making them feel part of normal society and overcome stigmatisation. Forty-five percent of people increased their spirituality after being diagnosed with HIV and there is consensus that an increase in spirituality has a positive effect on both CD4 and viral load counts (Dalmida, Holstad, DiLorio, Laderman, 2009; Ironson, Stuetze & Fletcher, 2006).

Spiritual counselling is all about listening, reflecting and sharing about difficulties the patient may have, particularly in dealing with or making life changes (Collins, 1980). Most palliative care patients are facing constant changes in their condition: dealing with loss or the change in life style that is required to accommodate the taking of ARV’s. Enabling patients to deal with their spiritual needs through affirmative relationships with health professionals improves quality of life and may reduce use of health resources (Grant, Murray & Kendall, 2004). In this study, many of the participants spoke positively of the spiritual support they received. One patient spoke emotionally of working through the experience of her mother’s death and the consequent fears of her own death: “I was scared that I would die ... I would leave my brother alone ... I could see in his eyes that he was also scared” “Mm, a sister would come next to your bed and ask if you need to pray? Do you need to chat about anything?” “[the chaplain] here always comes to talk and pray with us, she helped a lot”. One family member stated: “The patients are being taken care ... even that they can know God ... and that is why I want my sister to come here.”
Conclusion

The findings of the study indicated that patients want good holistic care. The most important aspects of care named by the patients and their families were compassion, respect, hope, autonomy, dignity, information and spiritual support. The care that patients want is simple and relational. This kind of care is that which is promoted as palliative care by the World Health Organisation. Therefore, holistic, relational palliative care should be promoted in public health. Further research should be done to investigate the attitudes and knowledge of health care professionals towards palliative care and its implementation in public health.

References


