

THE UNIQUENESS OF CARE: NURSES' STORIES OF PROVIDING PALLIATIVE CARE

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ABSTRACT

Palliative care involves caring for patients who face an illness that may shorten or profoundly limit their quality of life. Providing palliative care is complex as it must be reactive and individualised. The purpose of this article is to explore the experiences of nurses in providing palliative care to patients in a hospice. This qualitative research study used narrative theory to conduct unstructured individual interviews with three participants (hospice nurses) over a three-month period. The study took place at two purposively selected hospice sites. Potential participants had to be trained in palliative care and pain management in cancer and have at least one year's working experience in the area. The interviews were transcribed verbatim and analysed using thematic analysis. There were three themes that emerged from the data, namely, 'this Morphine story', celebrating living and 'there are no rules'. Understanding the nurses' experiences of providing palliative care can facilitate insight into the uniqueness of palliative care. The narratives uncovered in this study may be used to guide nurses around providing comprehensive complicated and complex care for terminally ill patients.

Keywords: palliative care, palliative care nurses, experiences, complexity



BACKGROUND

Palliative care involves caring for patients who face an illness that may shorten or profoundly limit their quality of life. People who face death are vulnerable and each patient and their healthcare professionals face illness, dying and death in their own unique way. By nature, palliative care is complex, finely nuanced and adaptive. Palliative care focuses on the holistic care of the patient and goes well beyond just providing medical care to encompassing other aspects of care such as cultural, spiritual, social and psychosocial care (Richardson, 2014). Palliative care also considers issues around social injustice and patients' rights (Selwyn, 2008). It considers, for example, access to pain control, justice-ethics and legal aspects of care. Caring for a patient who faces death or limitation to life is stressful and emotive and palliative care extends beyond the care of a patient to include care of the family and of the healthcare professional. The principles of palliative care include working within a multi-disciplinary team in order to meet the unique and multi-faceted needs of the patient, the family and the larger community.

Palliative care originated in the developed world and was relatively recently introduced into a developing world context such as Africa and there are concerns with this as these contexts differ greatly. For example, with regards to palliative care in a developed world context, assumptions may be made that a patient who requires palliation has had access to appropriate treatment modalities and that diagnosis and prognosis are accurate. Campbell and Amin (2012) indicated that such assumptions may not always hold true in South Africa.

The current study was undertaken in KwaZulu-Natal where the palliative care context differs greatly from a palliative care context in a developed world; for example, in South Africa, due to a high prevalence of infectious disease, such as HIV/AIDS and TB, mortality and morbidity remain very high (Zwanga, Garenneb, Kahnc, Collinsonc & Tolet, 2007). The PTB/HIV mortality emerged in 1994, and has been rising ever since (men: $P = 0.001$; women: $P = 0.020$, test for trend). In the past few years for both sexes combined, 63% (95% CI 51–74%) of PTB deaths were attributable to HIV/AIDS. Healthcare facilities may be very busy, have limited resources and be overcrowded. Within the general community, patients are often faced with physical, emotional and sexual abuse and ways of caring for the dying may be unique to this context and the multicultural nature of society also makes caring challenging. Training may not equip healthcare professionals with the skills and knowledge to provide palliative care within such a challenging environment (Campbell, 2011).

STATEMENT OF RESEARCH PROBLEM

The nurse is the palliative care team member who will have the greatest contact with the patient and this gives the nurse a unique opportunity to get to know the patient

and his or her family, to assess in depth what is happening, what is of importance to the patient, and to assist the patient and the family to cope with the effects of their advancing disease. Each patient and each nurse are unique and hearing their stories through narrative methods offers insight into the complexity of receiving and providing care. Narrative offers a lens to understand often invisible aspects of providing palliative care, including conflicts and difficulties (Rolls & Payne, 2008). Holloway and Freshwater (2007) indicated that narrative in palliative care has great importance as potentially being able to improve education and training, practice and patient care, and also as a means to explore the meaning of illness and the interactions between health professionals. There is a scarcity of qualitative literature on how health professionals experience palliative care. Abam (2005) noted that nurses and other health professional have stories to tell, and listening to these stories may give researchers deep insights into the lives of health professionals who care for very ill and dying patients.

The narratives of palliative care nurses have not been heard in a South African context and it is necessary to explore their narratives as the context of palliative care provision is relatively new and challenges faced by nurses are unique as they are not encountered in other contexts.

PURPOSE OF THE STUDY

The purpose of this study was to explore the experiences of nurses in providing palliative care to patients dying of a terminal illness in a hospice.

DEFINITIONS OF KEYWORDS/CONCEPTS

Professional nurses are registered with the South African Nursing Council who have been trained in palliative care and pain management in cancer, and have at least one year's working experience in the area (South Africa, 2005).

Palliative care is an approach that is aimed at improving the quality of life for the patients and their families facing a terminal illness through the prevention and relief of suffering while providing holistic care (WHO, 2002).

RESEARCH METHODOLOGY

The theoretical underpinning of the study was the narrative method, which is based on the awareness that there are multiple realities and no single version of a truth. Narrative method is described as a hybrid of various theoretical frameworks, including Constructivist Theory, Humanist Theory, Feminist Theory and Hermeneutist Theory (Polkinghorne, 1988). In essence, narrative method subsumes a group of theories

and approaches that rely on the written or spoken words or visual representation of individuals and focuses on the lives of individuals as told through their own stories. In this research, we define the term 'narrative' – often used interchangeably with story or story-telling – as a form of expression recognisable as a story, that is, discourses with a clear sequential order that connect events in a meaningful way (Bingley, Thomas, Brown, Reeve & Payne, 2008). This method was chosen as it has been used extensively in palliative care research and practice outside South Africa. It has been reported to be useful in palliative care research, education and practice (Bingley et al., 2008). It is considered to be of particular use in palliative care as 'Story-telling, in general appears to be sparked by experiences of a "breach" or 'disruption, in our usual pattern of life' (Bingley et al., 2008:654). Narrative method was also chosen as literature describes that narrative methods can have some therapeutic effect in reducing stress among participants (Pennebaker & Seagal, 1999).

Research setting and participants

The study took place at two purposively selected hospice sites. As an inclusion criterion participants had to be trained in palliative care and pain management in cancer and have at least one year's working experience in palliative care. The researchers approached the managers of the hospices and explained the nature of the enquiry. Using purposive sampling, the manager in the hospice was asked to identify potential participants who were then approached and invited to participate in the study – three nurses participated.

Data collection process

After obtaining ethics approval (HSS/1121/013) and permission from the research settings, appointments were made to visit the manager of the research settings to discuss the research study. The purpose of the research and the interview format were explained and participants were requested. After providing written consent, the participants were asked to participate in unstructured individual interviews (audio-taped with their permission), which were conducted in a private room during their 'on duty' time, as negotiated with the manager and the participants. The data were then collected (from July to September 2014) using narrative methods where the participants were asked the question: Can you tell me about your experiences of providing palliative care? In order to allow the participants to provide detailed descriptions of their experiences, the interviewer (not known to the participants) did not attempt to steer the interview, but rather let the participants follow their own path, just stopping to ask for clarification by saying, 'can you tell me more?' Data could not be traced back to the individual or the research setting. The researchers were aware of the potentially distressing nature of the questions and the participants were monitored at all times for any signs of emotional distress, and interviews would

then have been terminated and emotional support provided for the participant if necessary. This was, however, not required.

DATA ANALYSIS

Interviews were recorded and transcribed verbatim by an accredited, independent transcriber, and then analysed. The manual data analysis involved both researchers initially familiarizing themselves with the interview data and then exploring the themes identified using thematic analysis (Reissman, 2003).

RIGOUR

The researchers employed strategies considered to ensure trustworthiness of the data (Guba & Lincoln, 1981). Attention was given to credibility (checking the true value of findings) by means of independent coding as described in the analysis above. The researchers strived to convince the readers that the claims made had strong enough support in the data. Transferability was established by providing 'in-depth' descriptions of the research process so that the readers who wish to 'transfer' the results to a different context are then responsible for making their own judgment. The researchers also attempted to provide sufficient information that can then be used by the readers to determine whether the findings are applicable to the new situation and, to this end, the researchers included a number of quotations/'participant voices' from the verbatim transcriptions. Dependability was maintained through storage of the raw material, giving a full description of the research method, and applying the same procedure throughout.

FINDINGS

There were three registered nurses (ANN, RANI and THANDI – pseudonyms) who participated in the interviews and were between 30 to 70 years of age, and between them had over 35 years of palliative care experience. There were three themes that emerged from the data, namely: 'this Morphine story', celebrating living and 'there are no rules'.

'This Morphine story'

In providing palliative care, the concept of pain management appears to be central to everything, and Morphine is a drug used most often to manage the pain. The participants explained just how complex the issue of pain relief and of using and managing Morphine specifically is.

The participants explain:

Huge challenges, the biggest challenge is – what's the biggest challenge? Well, number one, keeping people pain-free. That's the biggest challenge, pain and symptom-free (ANN).

Well, sometimes it's very, very difficult to relieve people's pain and 'specially [sic] emotional pain. You know, it's very difficult, when you've got to bring in all the people that you can, you know, spiritual councilors', and social workers (ANN).

The participants described the struggles they go through attempting to keep their patient pain free. Due to the complex nature of the various terminal diseases, managing the pain is very difficult:

You know because, I think people who come to Hospice, you do want to do what's right and you do want to do what's good and you don't want to cause pain to anybody and to see people I think the largest dilemma for us is when certain people you know would hold morphine ... [inaudible] and they say "oh no my family is going to get addicted" (RANI).

If the morphine doesn't work, think sideways (ANN).

The participants described difficulties in using this medication to effectively manage the pain of their patient due to the reluctance to use the drug on the part of other health professionals;

And it was difficult with the doctors because themselves they know everything about [it], they were not clear about this palliative care. If at all the patient needs a morphine, they would order [a] less[er] dosage ... because now they'll say they're going to be addicted, whatever story. So they were not giving them enough dosage, and to raise the dosage, because now they'll say "it's too much" and all that story. But now it's difficult to give in-service training to the doctors (THANDI).

And after finishing it [palliative care training] we went back to Hospital X and we conducted a lot of in-service[s] because we had a problem ... because now when you have done palliative care, you need a doctor to work hand in hand with you, especially to order treatment ... and the doctors could not understand this morphine story and how to manage pain control (THANDI).

Celebrating living

The participants described that an important part of providing palliative care was still celebrating living and this was done by creating opportunities for the patients to enjoy time with their loved ones, to still enjoy life and in making memories. A participant described the following experience with a terminal patient:

One case in point was a gentleman who was a bit depressed and he just had like a few days left to live and we decided ... let's invite his family and so we got his family here and we pushed him in his bed down to the pool and his grandkids were swimming in the pool and he was on the bed and just watching and his son in law was braaing, ... and for the first time he

smiled, you know, after many weeks and then like a few days later he passed away and that's when I realized, ... they hold onto their memories ... it doesn't mean because they have a terminal illness that they must stop living (RANI).

Other celebrations were also described that allowed the patient to enjoy and celebrate time with their loved ones;

And then we had a young man who was here in the unit and his family lives far away in the rural areas and so they couldn't come as often as we would like. And then one week, you know one day, he suddenly told the Sister [registered nurse] "you know what, tomorrow I am going to pass away and I want my family, I want to have a meal with my family", and the odd thing is he had cancer of the mouth and he couldn't eat, ... but obviously you know ... we would do our best to fulfil his wish and so somehow working with the social workers and all of that, we got the family here and it was our table in the coffee bar area, so it was a lovely round table. And so the family ... and our kitchen prepared a meal ... and the family sat around and was eating and we brought him to the table in his wheelchair, he could barely sit up but he wanted to be part of that family meal. For him it was so important. Ja, and so he didn't eat, but he was there (RANI).

We had one chap, J, he had cancer of the colon ... he had a huge gaping wound in his abdomen, all horrible, that we had to pack. It was all pussy and dreadful and J wanted to get married. M was his girlfriend, and he had, I think, three children at that point. So we organized this wedding, but it was going to be in his home, in his own township, and our minister, our visiting minister, at the time, gave him a suit to wear. Somebody else gave him a shirt, and somebody else gave him a tie and our Doctor gave him a pair of shoes to wear, and our matron at that time, organized a wedding dress for M. So off they went, and they got married and they slept together that night, and he fathered a child (ANN).

THANDI and RANI explained further:

We ask them if at all, what problems do you have? ... especially sometimes with your things at home, with whatever ... with your children... so we can call the people who are relevant (THANDI).

Palliative care is about easing their symptoms, like their nausea, their depression, whatever it is ... and their spiritual issues, because you look at the patient holistically and then we look at how can I make them so comfortable that they enjoy whatever life is left. Whatever amount of time that they have left. And so that's the purpose of palliative care and so some people think it's depressing to work here but it's not because we actually feel that we are making a difference because we take away whatever suffering they, the person, has so that they can enjoy the time with the friends and family. And, ja, so that's what palliative care is, it's not dying, it's about living (RANI).

There are no rules ...

When describing their experiences of providing palliative care, the participants were at pains to explain that it is different in many ways to caring in a traditional hospital

setting. They contrast palliative care to the care they would provide in a hospital. A participant explained how the different type of caring within palliative care can affect the family:

At one point we, you know, we had a, we used to have a, a bar, a pub every night. At five o'clock we used to ... you get a husband coming in, and his wife's dying or something, and you say "would you like a beer?" Immediately they relax because it's different. They come in with all their guns firing, because they've been in [inaudible], or they've been in Hospital X for weeks. And they've had all this dreadful protocol, and cool coldness, and they come in here, and their guns are firing. It takes about two days sometimes, for people to settle down, and realize that this is a different place (ANN).

That's exactly what we say every time somebody comes in, "treat this place as your own home. Do what you like, come in here, watch TV, make tea, coffee ... do whatever you like. We've got sleeping couches, you can sleep on the floor at night if you want to ... to be with the loved one" (ANN).

RANI went further to say:

We offer care, spiritual care but it's nothing religious. We just look at what gives people meaning in their lives and what they draw strength from ... and for some people it is religion but for other people it can be things like music, classical music or ... [inaudible] or the family or a memory of perhaps going to another place, you know that's ... just thinking about them, about that makes them strong (RANI).

A participant summed it up by saying:

You've got the space to do things ... it teaches you to be very open minded, there's no one way of approaching a situation, it depends on the family and the person ... you know, it's different. It's the kind of nursing you dream about. My soul would die working in a hospital (ANN).

When considering the uniqueness of the palliative care and the necessity of training nurses regarding managing palliative care patients, THANDI said:

I'll make it a point that everybody goes for this training. All the nurses (THANDI).

DISCUSSION

The nurses in the current study described in great detail the complex issue of pain control in palliative care. This emphasis on pain management in palliative care is supported in a wealth of other literature. As an example, a survey carried out in Thailand identified pain management as one of the top five most important interventions carried out by nurses in promoting dignified dying (Doorenbos, Juntasopeepun, Eaton, Rue, Hong & Coenen, 2013). In outlining the three foundational aspects of ensuring an effective palliative care approach, WHO describes the need for

integration of palliative care services into the national health care system; training of health workers; and a drug policy to ensure the availability of essential drugs to manage pain (WHO, 2004). Ensuring pain relief and access to appropriate analgesia for the terminally ill patient is of great concern worldwide and specifically within the resource constrained environments of Africa (WHO, 2004). The participants in the current study have alluded to the difficulties in ensuring access of analgesia for their patients and, in many parts of Africa, there still exists a fear of opioids and this has led to occasions where health workers have restricted treatment of pain, thus resulting in patients experiencing unnecessary pain at the end of their life (Ntizimira, Nkurikiyimfura, Mukeshimana, Ngizwenayo, Mukasahaha & Clancy, 2014). It is also of concern to note that the consumption of morphine in the world is concentrated (over two-thirds) in a small number of countries, and in 2013 the United States was the country with the highest consumption of morphine, followed by Canada and the United Kingdom. A large part of the world population (81%) has just 9.5% of the amount of morphine available globally at its disposal to manage pain and suffering and given the significant need for palliative care in Africa, this is of great concern (International Narcotics Control Board, 2014).

Participants described the importance of palliative care providing opportunities for their patients to still celebrate living, to create opportunities for them to enjoy time with their loved ones and to make memories. The importance of celebrating living is supported in literature; McSherry (2011) found that patients who were involved in a life review and re-evaluation of their lives were more satisfied and interacted more with family and friends in an effort to relieve discomfort and regain control over their situation. This was viewed as an important part of their 'inner life at the end of life'. The philosophy celebrating living dovetails with the palliative care philosophy about affirming life and regarding dying as a normal process in one's life trajectory; it focuses on the uniqueness of each individual and is concerned with providing holistic care that encompasses the physical, psychological, social, cultural and spiritual needs of the patient (Wu & Volker, 2011).

Attempting to focus care related to the uniqueness of the patient and his or her needs does require that the nurse is flexible and adaptable to the patient's needs and when the nurse is willing to establish a close relationship with the patient, the ability to alleviate their suffering may be more likely (Wu & Volker, 2011).

Palliative care is complex and involves changing, challenging and unpredictable physical, psychological, social and spiritual care. By nature, palliative caring thus occurs within a 'complex system'. A complicated system (as opposed to a complex system) is one that is made up of many different components, which together form a complicated network that is 'fixed', that is, the components work in a predictable manner. A complex system, however, is different as it consists of many interacting components that are not as predictable. These components may be very diverse, autonomous but at the same time interrelated and interdependent or interconnected

with one another and the system as a whole. An excellent palliative care example to illustrate this is severe pain. In the palliative care patient, the severe pain may be due to the actual disease process, anger, depression, social isolation for example, and merely increasing the dose of Morphine may not be sufficient to effectively address the problem. In such a challenging environment, it is thus not possible or appropriate to have rigid rules for managing such a complex system (Munday, Johnson & Griffiths, 2003).

RECOMMENDATIONS

The researchers recommend that nurses, and other health professionals, working in various contexts caring for palliative care patients need to appreciate the complexities involved in such management and changes to the clinical areas as well as staff training and education need to be undertaken to address these challenges. Further research into the complex subject of palliative care within resource constrained environments is also encouraged.

LIMITATIONS

The data from this study included three participants and thus this is a snapshot from their perspective only.

CONCLUSION

Understanding the nurses' experiences of providing palliative care can facilitate insight into the uniqueness of palliative care. The narratives uncovered in this study may be used to guide nurses around providing comprehensive complicated and complex care for terminally ill patients.

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