

Experiences and Practices of Nurses Caring for Terminally Ill Cancer Patients: A Qualitative Study

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Abstract

The aim of this study was to explore the experiences and practices of nurses caring for terminally ill cancer patients at the Pietersburg Hospital, in the Limpopo Province, South Africa. Data was collected using semi-structured interviews. Data were analysed using Tesch's open coding data analysis method. Some of the nurses feel that caring for terminally ill cancer patients was emotionally demanding, strenuous and stressful because of the extensive pain that patients experience. The nurses bond with the patients to such an extent that they feel as if they are family. However, most of the oncology nurses blame themselves, feeling as if they do not do enough to help patients survive, when caring for the terminally ill cancer patients. Family members have expectations of nurses when their patient is in hospital; and when their expectations fail, they sometimes become aggressive and fault-finding. Most oncology nurses consider caring for terminally ill patient a stressful job; yet others expressed love for it. The findings of this study indicate that oncology patients need nurses to support and care for them at all times. Nurses who care for cancer patients have different experiences, some of which cause stress which is painful because they become close to patients and understand the pain they are suffering. Nurses, who care for cancer patients need care and support from hospital management in order to cope with their work.

Keywords: experiences, terminally illness, cancer patients

1. Introduction

Cancer is one of leading causes of death and disability worldwide and accounts for about 13% of deaths globally (World Health Organisation [WHO], 2008). The Cancer Association of South Africa reports that in 2008, about 80 000 people in South Africa died from cancer-related diseases (De Kock, 2011). The incidence of cancer is increasing in developing countries and the morbidity and mortality is expected to rise as people in developing countries adopt more of a western life style, which predisposes individuals to cancer (De Kock, 2011).

Nurses provide continuous health care to terminally ill cancer patients until they die, while doctors consult patients occasionally. Providing effective care at the end-of-life implies that a nurse should have a positive attitude towards the patient and provide emotional support to terminally ill cancer patients (American Genetic Society [AGS], 2007). Patients regard this as a significant time of their lives when nurses providing care are also expected to honour their patients' wishes by relieving the symptoms of the disease, while maximising their comfort (Sherman, Matzo, Pitorak, Fenell, & Malby, 2005).

Caring is when a nurse shows care and compassion towards terminally ill cancer patients (Wengström & Ekedahl, 2006). This can be very challenging for oncology nurses because of the complexity of the care required by patients with cancer (Kendall, 2007). Patients require physical, psychological and social care from the nurses. The impact of caring for patients with cancer, and their families, may prove to be overwhelming if support systems, particularly in the work environment, are not in place and the nurses are not taken care of (Medland, Howard-Ruben, & Whitaker, 2004). Nurses believe that their managers play an important role in ensuring care and in the facilitation of the healing of patients by creating a healthy and caring management environment (Minnaar, 2003). Minnaar (2003) claims that the human dignity of both patients and staff members must be looked after

during the care of patients with cancer.

Nurses caring for terminally ill cancer patients experience challenges, despite aggressive efforts to reduce high death rates and extend the life of the patients (Frommelt, 2003). Caring for terminally ill cancer patients is, therefore, a complex issue, especially when caring for elderly patients. Because of their age; the elderly are predisposed to complications and this adds to the burden experienced by nurses, making it more difficult for nurses to care for their patients (Press, Thom, & Kline, 2009). Furthermore, a nurse should be able to consistently adjust to the different needs of each patient with cancer and the needs of their families (Byock & Corbeil, 2003). The personality of the nurse is crucial when caring for terminally ill cancer patients because their personality is related to the comfort experienced by their patients. It requires great skill and understanding on the part of nurses who care for terminally ill cancer patients (Roberta & Rolland, 2009). The present study was undertaken to explore the experiences and practices of nurses caring for terminally ill cancer patients at the Pietersburg Provincial Hospital, in South Africa. Understanding the experiences and practices of nurses caring for terminally ill cancer patients, who are exposed to untimely death of their clients would inform counselling and support services for the nurses in vulnerable situations, such as caring for terminally ill cancer patients.

2. Methods

2.1 Study Design

A qualitative phenomenological, descriptive, exploratory and contextual research design was used because the researchers aimed to describe and explore the experiences and practices of nurses caring for terminally ill cancer patients in the Pietersburg Provincial Hospital. The researchers interviewed nurses working in oncology wards where terminally ill cancer patients are cared for. The researchers tried to refrain from any pre-conceived ideas and focused on collecting true facts as the participants outlined them during the interview sessions (Thomas, 2004).

2.2 Study Site

Limpopo Province is one of the nine provinces of the Republic of South Africa, situated in the far northern part of the country. There are two tertiary hospitals, 40 district hospitals and 440 clinics in Limpopo. The two tertiary hospitals are referral hospitals with different specialities. The Pietersburg Provincial Hospital, amongst other things, provides specialised care in oncology. The hospital has oncology wards staffed by nurses trained in oncology nursing. It has three wards where terminally ill cancer patients are admitted, namely medical oncology, paediatric oncology and a surgical ward.

2.3 Population and Sampling

The target population consisted of all nurses rendering care to terminally ill cancer patients in the Pietersburg Provincial Hospital. Sampling was taken from nurses working in the surgical and medical oncology wards and had three or more years' experience. Purposive sampling was used to select the medical and surgical oncology participants. Seven nurses from the surgical oncology ward and eight nurses from the medical oncology ward were interviewed until data saturation was reached (Burns & Grove, 2003).

2.4 Data Collection

Data was collected through individual face-to-face interviews and semi-structured interview guide. Each interview session lasted between 45–56 minutes. To ensure a reciprocal trusting relationship, each interview commenced by asking the participants about their wellbeing. An audio tape was used to record the interviews, and a notepad to make notes such as gestures, smiles or other facial expressions. The interviews were transcribed verbatim. The central question was, **“Can you kindly describe your experiences and the care you provide to the terminally ill cancer patients in this hospital?”** Probing questions were asked to gather more information, and to encourage the nurses to elaborate on the problem studied (Brink, 2006).

2.5 Data Analysis

Data were analysed using Tesch's qualitative data analysis as outlined by Creswell (2013). The researchers read and divided the data in small and significance parts. The researchers listened to the voice recorder attentively for clear understanding of the recoding. Any parts of the transcription that did not make sense were clarified by moving back and forth on the recording. Data was interpreted and classified according to themes and sub-themes.

2.6 Trustworthiness

Credibility was ensured by staying in the field for a period of two months in order to have sufficient time to collect data, by giving the study participants' detailed explanations of the research question on different. Dependability was ensured by describing the research methodology in detail, writing interview field notes and utilising a voice

recorder to capture all interview sessions. Transferability was ensured by a thick description of the research methodology, study participants were purposefully sampled and had three years' or more experience in the study field. Confirmability was ensured by using a voice recorder and written field notes to capture the interview sessions (Babbie & Mouton, 2009).

2.7 Ethical Considerations

Ethical clearance was obtained from the Medunsa Research Ethics Committee (MREC). Permission to collect data in the health facility was requested from the Limpopo Provincial Department of Health Ethics Research Committee. Permission was also requested from the Chief Executive Officer of the Pietersburg Provincial Hospital and the unit managers of the oncology wards. The researchers obtained informed consent, in writing, from participants before conducting the semi-structured interview sessions.

3. Results

The themes and sub-themes emerged during data analysis using Tesch's open coding data analysis method, as outlined in Creswell (2013), and the discussions of the results are supported by direct quotes from participants. Table 1 presents the themes and sub-themes pertaining to the experiences and practices of nurses caring for terminally ill cancer patients.

Table 1. Themes and sub-themes reflecting experiences and practices of nurses caring for terminally ill cancer patients

Themes	Sub-themes
Experiences during provision of care to cancer patients	<ul style="list-style-type: none"> • Analogous experiences during provision of care experience • Nurse-patient emotional attachment experience • Self-blame related to failure to relieve patients' symptoms • Development of avoidance behaviour related patients' suffering • Appreciation of care versus lack of appreciation from family members • Caring for cancer patients a stressful experience • Views related to reallocation to other units
Provision of care and support to patients during admission	<ul style="list-style-type: none"> • Provision of basic nursing care • Isolation of patients a bad idea • Enough versus minimal family support encouraged • Continuous management of pain effected • Provision of psycho-social support

Experiences during provision of care to cancer patients

The findings indicate that nurses have different feelings about caring for terminally ill cancer patients. Seven sub-themes emerged from this theme namely: Analogous experiences during provision of care experienced, nurse-patient emotional attachment experienced, self-blame related to failure to relieve patients' symptoms, development of avoidance behaviour related to patients' suffering, appreciation of care versus lack of appreciation from family members, caring for cancer patients a stressful experience and views related to reallocation to other units.

Analogous experiences during provision of care experienced

Some of the nurses feel that caring for terminally ill cancer patients was emotionally demanding, strenuous and stressful because of the extensive pain that patients experience. This was confirmed by a participant who said: "Mmh, when those patients arrive we feel like ooh gosh another pain because once you nurse those patients is touching than the other patient even HIV, HIV is nothing. Those patients the way they feel pains we can even give morphine four hourly the way they get severe pain."

Another participant expressed the same opinion, saying: "actually, caring for cancer patients is stressful, because this patients when coming to the hospital sick like that you sort of become so connected with this patients, take

them as your sister, brothers and then in a long run you find that you are there but the breaking or the sad thing is that at the end of the day you lose them."

Nurse-patient emotional attachment experience

The findings reveal that the nurses bond with the patients to such an extent that they feel as if they are family. This was clarified by participant who said: *"Yes, we are bonding and we are like we treat each other like a sister and a brother, like a father and a mother in a family."* Another participant with similar experiences said: *"We do bond with the patients to an extent that we do share our stories and we just become one big family."*

Another participant said: *"You do develop a relationship with the patient, a close relationship of friend or a mother and a child if she is younger than you so you can guide the patient that she shouldn't default treatment."*

Self-blame related to failure to relieve patients' symptoms

The findings reveal that most of the oncology nurses blame themselves, feeling as if they do not do enough to help patients survive, when caring for the terminally ill cancer patients.

This was confirmed by a participant: *"And that make one to question why is that happening and you can see you are losing a person completely, and it end to the point [ya gore] (that) it is sad, it depresses you and then you come to the point seeing this person disappearing in your eyes and you just wonder if there is anything you can do for the patients."*

A participant with similar feelings said: *"It is traumatising because every time you look at the patient you feel sad that you can't carry his pain to yourself, it is impossible you just look at him and only give medication to relieve pain."*

Development of avoidance behaviour related to patients' suffering

Oncology nurses feel relieved when they do not have to care for ill cancer patient because they hate to see patients suffer because of the disease. The findings indicate that some nurses feel relieved when they are off duty or allocated to the wards which admit very stable patients. This was confirmed by the participant who said: *"I went for day offs [resting days] but when I came back I was so relieved that I was allocated to take care of stable patients, because I didn't want to see that part where she struggle a lot because I was even avoiding to go to her side ward [cubicle for very ill patients] not because I don't want to help."*

A participant with similar feelings said: *"I want them to come to the hospital and go for chemo or be transferred to Johannesburg so that I don't see them on daily basis."*

Appreciation of care versus lack of appreciation of care by family members

Family members have expectations of nurses when their patient is in hospital. When their expectations fail, they sometimes become aggressive and fault-finding. A participant maintained: *"Yes we do involve them, is just that they are complaining about small things, sometimes they will tell you that nurses are not feeding their relatives the way they do."*

A participant who had the same experience said: *"No is like the family members don't accept the condition of their loved ones especially in this situation and some of them they are very aggression telling us we are not assisting their sick relatives."*

On the other hand, some families appreciate the work done by nurses. This was emphasised by a participant who said: *"We try as much as possible because most of the family members appreciate because they even thank us for taking care of their loved ones."*

Caring for cancer patients is a stressful experience

Working in an oncology setting is considered to be to be very stressful. The findings of the study indicate that most oncology nurses consider caring for terminally ill patient a stressful job. This was confirmed by a participant thus: *"It is so stressful because we understand this signs and symptoms that patient are having, for example when I first worked in here, I was used to work with them but not closed, so now I see them and when oncology patient complain of difficulty in passing stool and they complain of constipation, once I nurse these patients I also experience constipation"*.

Another participant with similar feelings said: *"It is stressful and challenging to take care of the cancer patients and this is because we lose our patients"*.

Views related to relocation to other unit

The findings of this study indicate that the relocation of nurses to other wards is seen as an option to help them cope

because they will be removed from the terminally ill cancer patients. This was outlined by a participant who said: *“Ooh no, I really want to relocate, I really want to get out of bedside nursing because of the emotional pain that I am experiencing every now and then, for the fact that am quite an emotional somebody, it makes me too vulnerable.”*

However, some participants indicated that, while caring for oncology patients is emotionally demanding, they love working in an oncology setting, despite the challenges. A participant with this view shared: *“No, I love to work in this ward. I don't want anyone to relocate me; I'm enjoying working with these patients especially the cancer ones.”*

Provision of care and support during admission

The findings of this study indicate that oncology patients need nurses to support and care for them at all times. Five sub-themes emerged under this theme, namely provision of basic nursing care, isolation of patients a bad idea, enough versus minimal family support encouraged, and encouragement of psycho-social support.

Provision of basic nursing care

The findings show that nurses ensure that basic needs of the patients are taken care off on a daily basis. Every day nurses try their best to care for patients who cannot do things for themselves. This was outlined by a participant who said: *“On daily basis, people from night staff they continue with giving of medication, they make sure that the basic needs like bed bathing are taken care off, they bath those patients who need to be bathed, they feed those who need to be fed, then we also give medication according to what the doctor has prescribed.”*

Another participant, who also provides daily care said: *“I am doing bed bathing, linen changing, am friendly to the patient, build trust between patients and myself.”*

Isolation of patients a bad idea

When oncology nurses see that a patient is terminally ill, they take that patient into the side ward or isolation ward so that other patients are not traumatised by the situation, hoping that the very ill patient will die peacefully.

One participant said: *“It is so discouraging because when the patient is very ill and we realise that this patient might die anytime, we have two side wards and we isolate the very ill patients from other patients so that they cannot see that she/he is not doing well.”*

Enough versus minimal family support encouraged

Family plays an important role in the wellness of the patient. Patients need their families to support them and help them to cope with the challenges that they are going through on a daily basis. The findings indicate that family members are encouraged to accompany the patients to the hospital to assist them with what they need. This was emphasised by a participant who said: *“so we want the family to assist in the care of the patients because at least if the patient comes with the family or somebody from home we give them an advise that somebody has to be easily accessible whenever the patient need a family member to assist.”*

Continuous management of pain effected

Oncology patients suffer extensive pain; even to the point of requiring four hourly analgesics. The pain may become so severe that not even analgesics are effective. This was outlined by a participant who said: *“Just imagine the patients are in pain, they are crying of pain every day. They are complaining with the treatment we give and then they will tell you ----- [doctor you are giving me this but am trying to take this tablets, but after taking it after few hours I am in pains again] ----- can you see that the patient is having continues pain which needs management.”*

This was supported by a participant who said: *“Giving of those pain analgesics is just, is only reassuring.”*

Provision of psycho-social support

Cancer is a chronic illness that can incapacitate a person to the extent that he or she is unable to go to work and care for his or her family, resulting in psychological and social problems as the patient worries about who is going to take care of the family. This effect of cancer highlights the fact that oncology patients need psychological and social assistance. One participant said: *“After interviewing the patient or talking to the patient and then we will talk to the doctor maybe to provide the patient for grant. We will also send the patient to the psychologist for psychological care to problems experiencing and also send the patient the social worker for social problem.”*

4. Discussion

This present study explores the experiences and practices of nurses caring for terminally ill cancer patients at the

Pietersburg Hospital, in the Limpopo Province, South Africa. The participants revealed that caring for terminally ill cancer patients is physically, emotionally and spiritually demanding. Additionally, working in an oncology setting is highly stressful because of the regular exposure to the pain and suffering that patients go through on a daily basis (Block, 2001). Developing a personal relationship with a cancer patient carries the risk of becoming emotionally overwhelmed which may result in unresolved grief and may reduce the nurse's subsequent ability to work (Sandra, Marzena, & Gabriella, 2015). Franke and Durlak (1990) maintain that there is a close relationship between oncology nurses and the dying cancer patients.

The present study demonstrated that most of the oncology nurses blame themselves, feeling a sense of guilt for not doing enough to help the cancer patient to survive. Whipped and Canellas (1991) indicate that the sense of failure among oncology nurses leads to feelings of helplessness, guilt, failure and anger, resulting in feelings of personal failure when treatment fails and patients die. Nurses feel responsible for the lives of their patients; their ambition is to provide high quality care to the patients and their relatives and failure to do that result in nurses blaming themselves for the failure when the patient dies. Oncology nurses usually demonstrate avoidance behaviour to cope with their discomfort about the death of the patients or the difficulty of caring for patients in severe pain. Caring for dying cancer patients sometimes makes nurses sad and uncomfortable, resulting in some oncology nurses avoiding terminally ill patient (Mystakidou, Parpa, Thilika, Kalaidopoulou, & Vlahos, 2002).

The findings of this study indicate that family members differ in character concerning appreciating the care by nurses. There are those who do not appreciate the efforts of nurses when caring for their sick relatives. In support of these findings, Pavlish and Cerosky (2007) state that some families believe that death is a preventable phenomenon which happens due to professional failure. However, Cincotta (2004) explains that family members have to deal with anticipatory grief, which includes feelings of guilt, disappointment and denial, which may lead to conflict and dysfunction within the family and antagonism towards the caregivers who, they perceive, do not do enough. Additionally, working in an oncology setting is very stressful; and this was acknowledged as such by the most of the oncology nurses interviewed in this study. Abeloff (2004) states working in the oncology environment is considered stressful since nurses are continuously exposed to incurable disease, pain and suffering of the patients. Additionally, Sinclair and Hamill (2007) state that nurses who deal with pain, fear and suffering related to death tend to suffer similar pain and stress. Oncology nurses are affected by a great number of stressors that need to be identified. When they are not identified nurses may feel that they are under stress and feel burnt out, which result in absenteeism, and a low retention of hospital managers (Barbour, 2016). However, the personalities of oncology nurses differ, with some nurses believing that working in a stressful environment does not have a physical or psychological impact on their lives or lead to illness (Marchand, Demers, & Durand, 2005).

Provision of nursing care takes place in hospices where oncology nurses involve patients and their families to facilitate caring for the patient holistically, meaning physically, psychologically and emotionally. This includes bathing, feeding, promoting rest and sleep for the patients (Vassallo, 2001). Isolation of a patient seems to be a bad idea because the patient will start to feel isolated from the real world while still alive. Lynette (2003) states that isolation is seen as a bad idea because it results in poor quality care and adversely affects the patients because they are not close to where nurses are. This means that even if they need help they won't be assisted timeously. It is the responsibility of the nurse to assist patients and their family members to develop coping strategies, to ensure that the family is always there for the patient and to provide care when at home (Hottenson, 2010). Hartrick (1997) states nurses are more often the ones who encourage patients and their families to engage in good interpersonal relationships which encourage the essence of relational caring. The quality of care of a dying cancer patient means adequate pain control and management of their symptoms (Allen, 2009). According to the Palliative Care Overview (2009), it is the responsibility of an oncology nurse to care for the patient as a whole or in totality, meaning taking care of their physical, psychological, social and spiritual needs.

5. Conclusion and Recommendations

Oncology nurses need psychological support to help them deal with the emotional challenges they come across when providing care to patients with cancer. Nurses report that they fail to attend to the patients' emotional challenges especially when looking at their patients' conditions deteriorating daily. Some oncology nurses feel that they would prefer to be moved from the oncology department if the challenges persist.

It is noted that there is a need to create good working conditions for nurses working in oncology units and recommended that these include the involvement of a psychologist who can assist both nurses and patients to cope with the situations they face daily. The nurses should be transferred from oncology wards if they are not coping with the care of the cancer patients. It is also indicated that families should always work together with nurses to provide care and support to the cancer patients. Family members should be made aware that death is a natural

outcome of the illness and that the nurses are not to be blamed for the death of their loved ones.

Competing Interests Statement

The authors declare that there are no competing or potential conflicts of interest.

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