

# Palliative Chemotherapy: The Perspectives and Experiences of South African Nurses

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## ABSTRACT

**Objective:** The objective of this study was to describe the perspectives and experiences of South African nurses caring for patients receiving palliative chemotherapy. **Methods:** A qualitative descriptive design was used and purposive sampling allowed us to select 11 nurses practising in a private ambulatory cancer care center in Port Elizabeth. In-depth interviews, guided by three broad themes were conducted and analyzed using qualitative content analyses. Data saturation determined the sample size. **Results:** Two themes emerged from the data – the patients cling to hope and the positive influence of palliative chemotherapy. The participants believed that patients consenting to palliative chemotherapy were clinging to false hope. They were also of the opinion that family members pressurize patients to consent to treatment. The participants experienced palliative chemotherapy positively, especially when an improvement in the patients'

quality of life or pain relief was evident. Fatigue was highlighted as the major side effect, but it did not temper the participants' positive attitudes toward the treatment. **Conclusions:** Although the participants believed that patients cling to hope and consent to palliative chemotherapy because they hope to be cured, they experienced the treatment as positive. For them, the improvement in pain and quality of life outweighed the side effects the patients experienced. The positive attitude patients upheld while receiving this treatment encouraged them. Nurses should gain more knowledge about the meaning, people living with advanced cancer, attach to hope to prevent them from interpreting patients' hope as denial and false.

**Key words:** Experiences, nurse perspectives, palliative chemotherapy, South Africa

## Introduction

Although cancer is a public health-care problem in South Africa, little is known about the experiences of nurses caring for patients receiving palliative chemotherapy.<sup>[1]</sup> With this study, we hope to address this knowledge gap by providing

a descriptive summary of the palliative chemotherapy experiences of nurses practising in a private ambulatory cancer care center forming part of the private health-care sector in South Africa.

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According to the 2012 Globocan statistics,<sup>[2]</sup> an estimated 39,900 people in Southern Africa would be newly diagnosed with cancer each year, whereas 25,100 would die from this group of diseases. South African men have a 1 in 8 and women a 1 in 9 lifetime risk of developing cancer. Cancers of the breast, cervix, prostate, and colon/rectum are the most common in the South African population. It is well known that not all people diagnosed with cancer will survive the disease and an estimated 4 out of every 10 cancer patients will enter the end of life phase and die from the disease.<sup>[3]</sup>

Palliative chemotherapy, referring to the administration of chemotherapy when cure is no longer possible, can be administered to enhance disease control.<sup>[4]</sup> Although this practice still raises questions about the benefit versus the burdens,<sup>[5]</sup> it is commonly used to prolong and improve the quality of lives of patients living with advanced cancer.<sup>[6]</sup> Unfortunately, patients do not always understand the goal of the treatment. Soylu *et al.*,<sup>[7]</sup> when investigating breast cancer patients' understanding of the goals of palliative chemotherapy, found 58% of patients included in their study believed palliative chemotherapy would cure them. Similarly, Weis and Boehncke<sup>[8]</sup> found that 69% of patients with lung cancer and 81% with colorectal cancer did not understand the goal of the treatment.

Once diagnosed with cancer, patients look to nurses for reassurance and understanding, as nurses are the human connection in the health-care realm.<sup>[9]</sup> The nurse-patient relationship is viewed as a central part of nursing practice and the cornerstone of good palliative care.<sup>[10]</sup> According to Mok and Chiu,<sup>[10]</sup> the depth and intensity of this nurse-patient relationship make it a friendship which demonstrates warmth and acceptance, which restore patients' faith in themselves. Trusting and connected relationships are built by the caring actions, attitudes and trustworthiness of the nurse. However, caring for a patient with incurable cancer, who struggles through multiple courses of palliative chemotherapy, is not easy and it is sometimes difficult for nurses to understand why patients with advanced cancer accept treatment with a lower chance of benefit than what would be considered worthwhile.<sup>[11]</sup> The attitudes of patients toward palliative chemotherapy differ from those of nurses, resulting in nurses struggling with the question of whether or not patients receive too many courses of futile chemotherapy.<sup>[12]</sup>

## Methods

### The study and participants

We chose a descriptive qualitative design, as it allowed us to describe the nurses' experiences accurately. In addition, the qualitative description provides findings which are closer

to the data as it is less interpretive than other qualitative designs.<sup>[13]</sup> The study setting was a private ambulatory cancer care center in Port Elizabeth, South Africa. Curative as well as palliative cancer treatment and care are offered, including chemotherapy and radiotherapy. The patient population includes mainly patients who have health insurance. Patients with different diagnoses are treated at the center, including those with breast, gynecological, colorectal, and head and neck cancers, leukemia, and lymphomas. A multi-professional team, which includes 15 nurses, practices at the cancer care center. Approximately 500 patients are treated with chemotherapy per month.

The participants comprised 11 purposively selected nurses practising in the selected setting. All were female, with ages ranging from 30 to 59 with an average of 40 years. Four were registered as specialist oncology nurses (RON), 5 were registered general nurses (RN) and 2 were enrolled nurses (EN). EN complete a 2-year learning program in nursing and have to practice under the supervision of a registered nurse. Only one participant had less than a year's experience in cancer care, whereas most had between 1 and 15 years' experience [Table 1].

### Data analysis

After we obtained ethical clearance and permission from the university and cancer care center, the second author, a registered oncology nurse, approached the nurses and invited them to participate in the study during their normal shifts; all recruited were willing to participate. Before conducting the interviews, informed consent was obtained in writing, and an information leaflet was handed to the participants. The interviews took place in a private room, either before the patients arrived for treatment or during lunch hour, lasting on average an hour. Participation was voluntary, and no harm was intended, however, we arranged with an oncology social worker to counsel participants who experienced emotional distress; none was referred.

**Table 1: Roles and experience of the participants**

Pseudonym	Role	Years of experience in oncology nursing
Anne	Registered oncology nurse	16
Lettie	Registered oncology nurse	4
Jessica	Registered nurse	1½
Mary	Enrolled nurse	10
Aletta	Registered oncology nursing	15
Christina	Registered nurse	1
Jane	Registered nurse	5
Jennifer	Enrolled nurse	15
Jill	Registered nurse	5
Kim	Registered nurse	4
Sarah	Registered oncology nurse	13
Gwyneth	Registered nurse	10 months

We conducted 11 qualitative interviews guided by three broad themes between October 2012 and July 2014. The themes were experiences of palliative chemotherapy, feelings toward the treatment and expectations of the treatment. Prompting questions and probes<sup>[14]</sup> were used to clarify issues and encourage the participants to expand on their experiences. Data saturation, the point where we obtained no new information<sup>[14]</sup> determined the sample size.

The data were transcribed verbatim; the names of the respondents were replaced with pseudonyms during the transcription. We used qualitative content analyses<sup>[13]</sup> to analyze the data. First, we read and reread the transcripts and made notes of interesting features in the margins, which served as our initial codes. Thereafter, we searched for themes within the data, which were reviewed several times before defining and naming them. The authors analyzed the data separately and held a consensus meeting to agree on the themes. We also used reflexivity to be aware of who we are, our perceptions as nurses and how it might influence the findings of the study.

### Enhancing rigor

We used the strategies of Lincoln and Guba,<sup>[15,16]</sup> namely credibility, transferability, dependability, and confirmability to enhance the rigor of our study. Credibility was enhanced by an early familiarity with the culture of the participating organization as the second author was employed by the organization for 9 years before the data gathering and was practicing as nurse in the specific setting. In addition, a research proposal, adapting a well-known research method, was developed and subjected to peer review. Confirmability was enhanced by voluntary participation and hence only those willing to offer data freely and honestly could be included. Confirmability was improved by using probes to elicit detailed data and an audit trail by recording the processes of the data gathering and analyses. Transferability was enhanced by presenting a detailed description of the context, the number of participants, data gathering methods and limitations. More than one person analyzed the data independently which enhanced dependability.

## Results

Two themes arose from the data: patients cling to hope, and chemotherapy is a positive experience. The themes are substantiated with verbatim quotations.

### *Patients cling to hope: "They still think there's hope"*

Most of the participants were of the opinion that patients were clinging to false hope. Participants believed that patients, in spite of being told by the oncologist that the palliative chemotherapy cannot cure them, still believed in miracles and hoped for a cure. Some participants believed

patients had not made peace with impending death, hence this hope. Aletta (RON) said, "With some of the patients you can see that they haven't made peace with the fact that this is the last for them. They still think there's hope, that's why they still come to the chemo room... they're still clinging to hope... they are under the impression... have a misconception, that something will still happen... that they'll be cured." Jane (RN) explained: "I don't think they understand that it's only to prolong their life. There's always the hope that I might be cured. God will cure me... let me try... you never know... miracles might happen... human beings want to live, nobody wants to die. Everyone wants as much time to live life as possible..."

Some of the participants felt the palliative chemotherapy decision was not always made by the patients independently, but by pressure from their families to consent to treatment. Gwyneth (RN) explained, "... the patient didn't want chemotherapy...but the family wanted him to have chemo... he knew what the prognosis was...He started chemo and suffered with a lot of pain and nausea. When I look at the older people, I think a lot of them succumb to family pressure because it's the children who want to keep them alive. I've seen a few where it's more the children that want it." Jennifer (EN) added, "There is lots of pressure from the families. They pressurize the patient to try something. The more the patient says no...the more the family wants them to keep trying."

Participants also considered that patients were often dishonest with the doctor regarding their symptoms or well-being to continue with treatment. Aletta (RON) said, "Yes... they are definitely different in front of the doctor... they try to be perfect during consultation... as if all is going well... but when they get to the oncology sister, it's as if the book opens up and the real situation is made known. They hide things because of fear that the doctor will stop their treatment if they are honest about their symptoms...they are not honest with themselves." Jill (RN) agreed, "... patients sometimes put up a front when they come here... they are actually much sicker at home... but if they look well, then all is well and they can continue treatment."

The participants believed that patients consenting to palliative chemotherapy were clinging to hope - hope for a better quality of life, symptom control and extra time with their families. However, they thought the patients' hope for a cure or a miracle was false. The participants believed family members pressurized patients into having palliative chemotherapy, rather than it being the patients' choice. The participants experienced some patients were not honest with the oncologist during consultations and did not reveal the truth about how sick they really were to prevent discontinuation of the treatment.

### **The positive influence of palliative chemotherapy: “Palliative chemotherapy is a positive experience for me”**

The participants stated they experienced patients as being positive when the chemotherapy “worked,” and their quality of life improved, which had a positive influence on the participants. Kim (RN) explained, “I feel positive when I see that treatment worked... patients have a better quality of life... can do more. They can do things that they couldn’t before they had chemo... it lengthen their lives and improves their quality of life.” Jennifer (EN) said, “... yes... I’ve seen a lot of sick patients improving on palliative chemotherapy, it’s truly amazing... at least they have a good quality of life for a few months.”

Participants also commented that patients experienced relief of pain when receiving palliative chemotherapy. Gwyneth (RN) said, “The patient had severe pain, and the doctor felt that the chemotherapy would help... and it definitely did. After the first chemotherapy session, the patient was fine and couldn’t believe that it had helped.” Sarah (RN) added, “I don’t know if they know that their symptoms will improve... unless doctor tells them. I do think that they are sometimes amazed when their symptoms do improve, like with bone metastases that improve... when they walk with more ease...”

The participants experienced that most patients had a positive attitude toward palliative chemotherapy and found this very positive and encouraging. Jane (RN) explained, “People are really positive. I chatted to one lady... she said ‘I know there’s no cure... I’m not going to be cured from this’... but she was happy to continue. Some of them do understand that they won’t survive it... but for now it works for them.” Lettie (RON) said, “I think most patients are positive about palliative treatment. They come back...there’s a recurrence...a progression... they come back and have more chemotherapy... they keep coming back.” Although the participants’ opinion was that palliative chemotherapy improved the quality of life of patients, they were quite aware of the side effects they experienced. Fatigue was described as “the main one,” while nausea and vomiting were not seen as prevalent problems. Sarah (RON) said, “They all complain of fatigue...especially the younger patients who still work and have young children... they can’t complete daily tasks... can’t cook... can’t pay attention to their children...” Jill (RN) added, “These days’ people don’t complain so much about nausea...but fatigue... It is as if fatigue is overwhelming for most patients...they are extremely tired and sleep doesn’t always help for this.”

In general, the participants experienced palliative chemotherapy positively, especially when an improvement

in the patients’ quality of life or when pain relief was evident. The patient’s positive attitudes encouraged them. Fatigue was highlighted as the major side effect, but it did not temper the participants’ positive attitudes towards the treatment.

## **Discussion**

Our study provides evidence the nurses believed patients consent to palliative chemotherapy primarily because they hope to be cured. The participants experienced this hope as false as patients were informed palliative chemotherapy would not cure them. They were also of the opinion that choosing palliative chemotherapy was a sign of not making peace with impending death. Andrew and Whyte,<sup>[11]</sup> when describing the experiences of district nurses caring for patients receiving palliative chemotherapy, found nurses were also of the opinion that palliative chemotherapy provides hope to patients and can raise unrealistic expectations, which is also supported by Doyle *et al.*<sup>[17]</sup> Daneault *et al.*<sup>[18]</sup> confirm our participants’ experience by stating false hope can deny the reality of imminent death and might not allow the patient to make final arrangements. In contrast, Nierop-van Baalen *et al.*,<sup>[19]</sup> in a study explaining the meaning of hope of patients in the palliative phase, shed a new perspective on hope which defies the concept of false hope. According to these authors, patients hope because they have no other choice. Without hope, life would not be worth living. Additionally, most patients hope to be cured, do not give up hope that they may live longer and do not redirect their hope to more realistic objectives, as some health care professionals would expect.

Our participants experienced that patients did not always consent to palliative chemotherapy because they wanted to, some were pressurized by their families. It appears the role of others in palliative chemotherapy decisions varies. For instance, Koedoot *et al.*,<sup>[20]</sup> in a study conducted in The Netherlands, found patients who have to decide whether or not to have palliative chemotherapy make this decision before consulting their doctor. However, Potgieter<sup>[12]</sup> in a South African study, found that patients make the palliative chemotherapy decision independently as they want the treatment either for their own benefit or for the benefit of their families. Bergqvist and Strang,<sup>[21]</sup> in a study focusing on Swedish women with metastatic breast cancer, found their participants preferred the doctor to make the decision about the continuation of palliative chemotherapy. Bergqvist and Strang<sup>[21]</sup> also indicated that the women in their study did not consider ceasing treatment, which supports the experiences of our participants that some patients are not open and honest about their well-being as they are scared their treatment might be stopped.

Our study provided evidence that although the participants were aware of the side effects of the treatment, their experience of palliative chemotherapy was overwhelmingly positive. For them, the improvement of pain, quality of life and the positivity of the patients outweighed the negative effects. In contrast, Andrew and Whyte<sup>[11]</sup> found some district nurses acknowledged the improvement of symptoms and quality of life, but experienced uncertainty and ambivalence about this treatment. It seems as if the palliative chemotherapy debate in terms of the advantages and disadvantages and the timing of the intervention is still ongoing. Prigerson *et al.*<sup>[6]</sup> advocate for the revising of the American Society of Clinical Oncology's guidelines as they found palliative chemotherapy can be potentially harmful for patients with terminal cancer. In contrast, Roeland and LeBlanc<sup>[22]</sup> state palliative chemotherapy can be a powerful intervention if used appropriately. Despite this uncertainty, being able to receive treatment generates hope for patients, which, when strengthened by a decrease of pain, means patients with advanced cancer are likely to accept treatment with a lower chance of benefit than what nurses would consider worthwhile.<sup>[11]</sup>

It was positive to find that our participants experienced nausea and vomiting to cease over time. However, fatigue was reported as the most distressing side effect, which seemed to be irreparable for some patients. Servaes and others,<sup>[23]</sup> when reviewing the literature, established that the prevalence of severe fatigue in patients with advanced cancer was 75%. In addition, Potter<sup>[24]</sup> found a similar trend experienced by our participants and reported fatigue has a negative influence on the quality of life and makes normal activities of daily living an uphill struggle, whereas Benzein and Berg<sup>[25]</sup> reported that patients who experience fatigue have a low level of hope.

## Conclusion

Although the participants believed that patients cling to hope and consent to palliative chemotherapy because they hope to be cured, they experienced the treatment as positive. For them, the improvement in pain and quality of life outweighed the side effects the patients experienced. The positive attitude patients upheld while receiving palliative chemotherapy encouraged nurses. Nurses should gain more knowledge about the meaning, people living with advanced cancer, attach to hope to prevent them from interpreting patients' hope as denial and false. In addition, greater knowledge would enable them to promote hope also by acknowledging the role that palliative chemotherapy may play in maintaining hope and patients' emotional well-being; as well as that hope presents itself in different

ways in different contexts. This would allow nurses to render more effective psychosocial and spiritual care to those receiving palliative chemotherapy.

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### Conflicts of interest

There are no conflicts of interest.

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