# Cancer patients' and health care professionals' perceptions and experiences of cancer treatment and care in South Africa

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# Contents

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# Summary

Cancer is a potentially life-threatening disease, which affects millions of people worldwide. It is multifaceted in nature and can lead to impairment in a person's physical, social and emotional functioning (Beatty, Oxlad, Koczwara, & Wade, 2008). Multidimensional treatment, with highly specialised professionals, equipment and services is thus needed for the effective treatment thereof (Mathews, West, & Buehler, 2009).

Patients treated within the private and public healthcare sectors of South Africa have vastly differing treatment experiences. Only about 20% of the South African population has access to and can afford treatment within the private healthcare sector (Somdyala, Bradshaw, Gelderblom, & Parkin, 2010). While private sector patients have access to information, social workers and support groups, those in the public sector face life-threatening waiting times and a lack of empathy by public sector staff, weighed down by patient numbers and a lack of resources (Pillay 2002; Bateman, 2011). A study previously conducted by the researchers highlighted cancer patients' perceptions and experiences of treatment as being one of the most prominent themes influencing patients' overall cancer experience (Venter, Venter, Botha, & Strydom, 2008). This, coupled with the fact that the majority of research studies previously conducted in South Africa generally focused on the biomedical aspects of cancer (Albrecht, 2009), make exploring patients and healthcare professionals' perceptions and experiences of cancer treatment in a South African context potentially valuable.

The thesis consists of three sub-studies reported in three manuscripts. The aim of the first article was to provide a narrative literature review exploring cancer survivorship and management in the South African context by scrutinising research previously conducted on cancer treatment. The aim of the second and the third article was to explore patients and healthcare professionals' perceptions and experiences of cancer treatment in the private and public healthcare sectors in the Eastern Cape, South Africa. A 100 participants were purposively sampled from a government-funded hospital (n = 30 patients; n = 22 healthcare professionals) and a private treatment facility (n = 30 patients; 18 healthcare professionals). Data was collected by making use of both qualitative (self-report questionnaire consisting of open-ended questions; interviews) and quantitative (Needs Evaluation Questionnaire) measures. A qualitative content and statistical analysis was conducted.

Findings indicate that despite the expressed need for treatment to move towards a more biopsychosocial approach, the majority of the healthcare professionals in the current study are still primarily following a biomedical approach. Findings also indicate that the majority of the difficulties and frustrations experienced could be seen as being contextual problems and were not necessarily related to cancer treatment per se. Poor availability of resources and the South African population's diverse characteristics were responsible for the majority of the difficulties reported. Differing cultural beliefs, language barriers, illiteracy and unemployment were al seen as negatively influencing the treatment process. This is consistent with Serin et al. (2004), who reported that there is a significant relationship between the systemic nature of medical issues and the social, material and psychological difficulties cancer patients' experience. The systemic nature of healthcare needs highlighted in the current study emphasises the necessity for cancer treatment in South Africa to employ a more biopsychosocial approach. True collaboration between healthcare professionals working towards a common goal should thus be considered as being the ideal.

Considering the socioeconomic divide and resource discrepancy between the private and public healthcare sectors in South Africa, credence must be given to the allocation of resources in the public sector. If this incongruity is to be addressed, there would have to be cooperation at government level. Assistance with regard to the allocation of funds, as well as the meticulous monitoring of the distribution thereof, is needed. Funding should be used to increase human and technical resources, as well as for staff development. Equitable care for all cancer patients, regardless of their socioeconomic status, is the ideal. The following recommendations on how to improve overall cancer care, in both sectors, can also be made: existing treatment sites need to be updated and additional sites developed; continuous research needs to be conducted; funds need to be allocated towards the development of effective transport and translation services; cultural diversity should be taken into account when developing awareness campaigns and treatment plans; healthcare professionals need to adopt a holistic approach during which attention is given to communication, establishing rapport and patient participation; and lastly healthcare professionals should also be encouraged to pay attention to their own healthcare needs as well.

**Keywords:** cancer patients, healthcare professionals, treatment, public sector, private sector, South Africa

# Opsomming

Kanker is ’n potensieel lewensgevaarlike siekte wat miljoene mense wêreldwyd beinvloed. Dit is multidimensioneel van aard en kan tot die verswakking van ’n persoon se fisiese, sosiale en emosionele funksionering lei (Beatty, Oxlad, Koczwara, & Wade, 2008). Om die siekte doeltreffend te behandel, word multidimensionele behandeling met hoogs gespesialiseerde professionele persone, toerusting en dienste vereis (Mathews, West, & Buehler, 2009).

Pasiënte wat behandeling in Suid-Afrika se privaat en openbare gesondheidsorg-sektore ontvang, het aansienlik verskillende behandelingservarings. Slegs ongeveer 20% van die Suid-Afrikaanse bevolking het toegang tot of kan behandeling in die privaat gesondheidsorgsektor bekostig (Somdyala, Bradshaw, Gelderblom, & Parkin, 2010). Terwyl pasiënte in die privaat sektor toegang tot inligting, maatskaplike werkers en ondersteuningsgroepe het, word diegene in die openbare sektor blootgestel aan lewensgevaarlike wagtye en ’n gebrek aan empatie omdat personeel in die openbare sektor belas is met groot getalle pasiënte en ’n gebrek aan hulpbronne (Pillay, 2002; Bateman, 2011). In ’n vorige studie wat deur die navorsers onderneem is, is kankerpasiënte se persepsies en behandelingservarings uitgelig as een van die vernaamste temas wat hulle algehele kankerervaring beïnvloed (Venter, Venter, Botha, & Strydom, 2008). Om hierdie rede en die feit dat die meerderheid van navorsingstudies in Suid-Afrika oor die algemeen op die biomediese aspekte van kanker fokus (Albrecht, 2009), is dit potensieel waardevol om pasiënte en gesondheidsberoepsmense se persepsies en ervarings van kankerbehandeling in ’n Suid-Afrikaanse konteks te verken.

Hierdie proefskrif bestaan uit drie sub-studies wat in drie manuskripte uiteengesit word. Die doel van die eerste artikel is ’n narratiewe literatuurstudie wat kankeroorlewing en -bestuur in ’n Suid-Afrikaanse konteks verken deur middel van ’n noukeurige ondersoek van vorige navorsing wat oor kankerbehandeling gedoen is. Die doel van die tweede en derde artikel is om pasiënte en gesondheidsberoepsmense se persepsies en ervarings van kankerbehandeling in die privaat en openbare gesondheidsorgsektore van die Oos-Kaap, Suid-Afrika te verken. ’n Doelgerigte steekproef van ’n 100 deelnemers is uit ’n staatsbefondsde hospitaal (n = 30 pasiënte; n = 22 gesondheidsberoepsmense) en ’n privaat behandelingsfasiliteit (n = 30 pasiënte; 18 gesondheidsberoepsmense) gekies. Data is deur middel van beide kwalitatiewe (selfverslag-vraelys met oop vrae; onderhoude) en

kwantitatiewe (*Needs Evaluation Questionnaire*) meetinstrumente versamel. Daarna is kwalitatiewe inhouds- en statistiese analise uitgevoer.

Die bevindinge toon dat, ten spyte van die uitgespreekte behoefte om na ’n meer biopsigososiale behandelingsbenadering te skuif, die meerderheid van gesondheids-beroepsmense in die huidige studie steeds hoofsaaklik ’n biomediese benadering volg. Die bevindinge toon ook dat die meerderheid van die probleme en frustrasies wat ondervind word as kontekstuele probleme beskou kan word en nie noodwendig aan die kankerbehandeling verwant is nie. Die swak beskikbaarheid van hulpbronne en die diverse eienskappe van die Suid-Afrikaanse bevolking is verantwoordelik vir die meerderheid van die probleme wat vermeld is. Verskillende kulturele oortuigings, taalstruikelblokke, ongeletterdheid en werkloosheid het ook almal ’n negatiewe impak op die behandelingsproses. Dit stem ooreen met Serin et al. (2004) se bevinding dat daar ’n beduidende verhouding is tussen die sistemiese aard van suiwer mediese kwessies en die sosiale, materiële en psigologiese probleme wat kankerpasiënte ondervind. Die sistemiese aard van die gesondheidsorg-probleme wat in die huidige studie uitgelig word, beklemtoon die noodsaaklikheid vir kankerbehandeling in Suid-Afrika om ’n meer biopsigososiale benadering te volg. Die ideaal kan beskou word as sinvolle samewerking tussen gesondheidsberoepsmense om ’n gemeenskaplike doel te bereik.

In ag geneem die sosio-ekonomiese gaping en die verskil in hulpbronne tussen die privaat en openbare gesondheidsorgsektore in Suid-Afrika, moet meer waarde aan die toewysing van hulpbronne in die openbare sektor geheg word. Om hierdie wanverhouding reg te stel, moet samewerking op regeringsvlak plaasvind. Bystand moet ook verleen word aan die toedeling van fondse, asook die noukeurige kontrolering en verspreiding van hierdie fondse. Fondse moet aangewend word om menslike en tegniese hulpbronne uit te brei, asook om personeel te ontwikkel. Die ideaal is billike sorg vir alle kankerpasiënte, ongeag hulle sosio-ekonomiese status. Daarby kan die volgende aanbevelings gemaak word oor hoe om die algehele vlak van kankersorg in beide sektore te verbeter: bestaande behandelingsfasiliteite moet opgedateer word en bykomende fasiliteite moet ontwikkel word; navorsing moet deurlopend plaasvind; fondse moet toegewys word aan die ontwikkeling van doeltreffende vervoer- en vertalingsdienste; kulturele diversiteit moet in ag geneem word in die ontwikkeling van bewusmakingsveldtogte en behandelingsplanne; gesondheidsberoepsmense moet ’n holistiese benadering volg wat op kommunikasie, die bou van ’n goeie verstandhouding en pasiëntdeelname fokus, en laastens moet

gesondheidsberoepsmense aangemoedig word om ook aandag aan hulle eie gesondheidsorgbehoeftes te gee.

**Sleutelwoorde:** kankerpasiënte, gesondheidsberoepsmense, behandeling, privaat sektor, openbare sektor, Suid-Afrika

# Preface

- This thesis is presented in article format in accordance with rule A.8.2.b of the North-West University.

- The three articles comprising this thesis have been submitted to the *Journal of Psychology in Africa*. The first article has been successfully published in 2012 and articles 2 and 3 are under review.

- The referencing style and editorial approach as prescribed by the *Publication Manual* (6th edition*)* of the American Psychological Association (APA) were implemented, save for instances where the intended journal for publication indicated otherwise. A copy of the guidelines for prospective authors as set out by the *Journal for Psychology in Africa* is attached.

- The page numbering of the thesis as a whole is consecutive. It should however be noted that each article was numbered individually starting from 1 on submission to a journal.

- The co-authors of these articles, Proff. C.A. Venter and K.F.H. Botha, has submitted a letter consenting that the articles may be submitted for examination purposes to obtain a Ph.D. degree.

# Guidelines for Authors

# INSTRUCTIONS TO AUTHORS

The **Journal of Psychology in Africa** includes original articles, review articles, book reviews, commentaries, special issues, case analyses, reports, special announcements, etc. Contributions should attempt a synthesis of local and universal methodologies and applications. Specifically, manuscripts should:
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Before submitting a manuscript, authors should peruse and consult a recent issue of the *Journal of Psychology in Africa* for general layout and style. Manuscripts should conform to the publication guidelines of the latest edition of the American Psychological Association (APA) publication manual of instructions for authors.

## Manuscript format

All pages must be numbered consecutively, including those containing the references, tables and figures. The typescript of manuscripts should be arranged as follows:
**Title:** This should be brief, sufficiently informative for retrieval by automatic searching techniques and should contain important key-words (preferably <10 words).
*Author(s) and Address(es) of author(s)*: The corresponding author must be indicated. The author's respective addresses where the work was done must be indicated. An e-mail address, telephone number and fax number for the corresponding author must be provided.
**Abstract:** Articles and abstracts must be in English. Submission of abstracts translated to French, Portuguese and/or Spanish is encouraged. For data-based contributions, the abstract should be structured as follows: *Objective*—the primary purpose of the paper, *Method* – data source, subjects, design, measurements, data analysis, *Results* – key findings, and *Conclusions* – implications, future directions. For all other contributions (except editorials, letters and book reviews) the abstract must be a concise statement of the content of the paper. Abstracts must not exceed 120 words. It should summarize the information presented in the paper but should not include references.

**Referencing:** Referencing style should follow APA manual of instructions for authors.
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Peltzer, K. (2001). Factors at follow-up associated with adherence with directly observed therapy (DOT) for tuberculosis patients in South Africa. *Journal of Psychology in Africa*, 11, 165-185.

Sternberg, R. J. (2001, June). *Cultural approaches to intellectual and social competencies*. Paper presented at the Annual Convention of the American Psychological Society, Toronto, Canada.

Cook, D. A., & Wiley, C. Y. (2000). Psychotherapy with members of the African American churches and spiritual traditions. In P. S. Richards & A. E. Bergin (Ed.), *Handbook of psychotherapy and religiosity diversity* (pp. 369-396). Washington DC: American Psychological Association.

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## Letter of Permission

The co-authors, Proff. C.A. Venter and K.F.H. Botha, hereby grant permission that the first author, M. Venter, may submit the following 3 articles for the purposes of examination and obtaining a Ph.D. degree in Psychology:

1. Cancer treatment in South Africa: A narrative literature review.
2. Patients' experiences of cancer treatment in the private and public healthcare sectors in the Eastern Cape, South Africa.
3. Healthcare professionals' experiences of working in oncology in the private and public healthcare sectors in the Eastern Cape, South Africa.

_________________________ _________________________

Prof. C.A. Venter
Promoter

Prof. K.F.H. Botha
Co-Promoter

# Chapter 1: Introduction

## Problem Statement and Substantiation

The high incidence of cancer and the accompanying medical and psychological effects thereof (Bennion & Molassiotis, 2013), requiring multidimensional treatment with highly specialised professionals, equipment and services (Mathews, West, & Buehler, 2009) make exploring patients and healthcare professionals' perceptions and experiences of cancer treatment potentially valuable. Cancer is not a single disease, but rather an umbrella term used to describe more than a hundred different diseases involving the uncontrolled growth and spread of abnormal cells (Garcia et al. 2007). If this dividing of cells is not stopped, it can spread throughout the body through the lymphatic system or the blood stream (CANSA, 2012). Cancer can involve any tissue of the body and has many different forms in each body area. Most cancers are named according to the type of cell or organ in which they originate (National Cancer Institute, 2012). Cancer can be caused by both external factors, such as tobacco, chemicals, radiation and infectious organisms, as well as internal factors such as inherited mutations, hormones, immune conditions and mutations that occur from metabolism (Garcia et al. 2007).

Worldwide, more deaths are caused by cancer than by AIDS, tuberculosis, and malaria collectively (Garcia et al. 2007). Approximately 12,7 million cancer cases and 7,6 million cancer deaths are projected to have occurred in 2008 worldwide, with 56% of the cases and 64% of the deaths being in the economically developing world (Jemal et al. 2011). According to the National Cancer Registry of South Africa (National Institute for Occupational Health, 2013), 25 678 new cancer cases were diagnosed in males and 27 205 new cases in females in South Africa in the year 2005.

Although the biopsychosocial perspective is generally accepted as being the best way to treat patients, in South Africa, the implementation of this strategy remains sadly lacking (Pillay, 2001). Cancer treatment typically involves surgery, radiation, chemotherapy, hormones, and/or immunotherapy (Garcia et al. 2007). While some types of cancer are relatively easy to detect and treat, others spread quickly and cannot be cured (CANSA, 2012). It is believed that worldwide more than fifty percent of all new cancer cases and cancer deaths are potentially preventable (Garcia, 2007). Early detection of cancer is associated with improved treatment outcomes. Unfortunately, the insufficient resources often found in developing countries result in a healthcare system that cannot provide adequate screening programmes and early treatment services (Garcia et al. 2007). In South Africa competing healthcare priorities (Michelow, McKee, & Hlongwane, 2006), poor resources (Pillay, 2002), cultural diversity (Wright, 1997), language barriers (Mullin et al. 2000) and the differential standards of treatment found in the private and public healthcare sectors (Bateman, 2011), result in a cancer care delivery system that does not reflect the new realities of cancer survival (Maree & Wright, 2008).

In South Africa primary healthcare is provided by the government, with cancer care facilities only being available in the bigger cities (Lourens, 2013). According to Somdyala, Bradshaw, Gelderblom, and Parkin (2010), only about 20% of the South African population has access to and can afford treatment within the private healthcare sector. Furthermore, the screening and treatment access gulf between the public and private healthcare sectors is evident in their hugely differing treatment routes and outcomes (Bateman, 2011). While private sector patients have access to information, social workers and support groups, those in the public sector face life-threatening waiting times and a lack of empathy by public sector staff, weighed down by patient numbers and a lack of resources (Pillay, 2002; Bateman, 2011). Additionally, practising preventative healthcare in the public sector is extremely difficult as its daily routine simply does not allow for any kind of cancer screening (Bateman, 2011). Public sector patients are, therefore, more likely to only be diagnosed at advance stages of cancer, which negatively influence treatment outcomes.

A study previously conducted by the researchers highlighted cancer patients' perceptions and experiences of treatment as being one of the most prominent themes influencing patients' overall cancer experience (Venter, Venter, Botha, & Strydom, 2008). According to Ogden (2004), there appears to be a conditioning effect regarding the perceived competence of healthcare professionals and patients' beliefs regarding the effectiveness of treatment. This was also evident in the study of Venter et al. (2008), as positive perceptions regarding the medical profession and treatment appeared to be associated with the report of more positive illness experiences. This, coupled with the fact that the majority of research studies previously conducted in South Africa generally focused on the biomedical aspects of cancer (Albrecht, 2009), makes exploring South African cancer patients' treatment experiences potentially valuable as the accurate assessment of patients' needs is central to improving adherence to treatment, treatment satisfaction, and quality of life (Annunziata, Muzzatti, & Altoé, 2009).

Working in oncology has been described as being similar to an expedition. Like climbing Everest, working in oncology involves thorough preparation, multidisciplinary teamwork, clear division of labour, intense work, considerable cost and plentiful rewards, immense obstacles, the need for replenishing and work that the general population cannot bear undertaking (Rohan & Bausch, 2009). Being continually confronted with illness, suffering and the potential of death on a daily basis creates an occupational milieu that can have a profound impact on the healthcare professionals working within this environment (Rohan & Bausch, 2009). How healthcare professionals perceive factors such as the limits of medicine, feelings of helplessness (Quattrin et al. 2006), being of service (Rohan & Bausch, 2009), intellectual stimulation (Medland, Howard-Ruben, & Whitaker, 2004), personal growth (Van Rooyen, Le Roux, & Kotzè, 2008), culturally informed values and beliefs (Bettencourt, Talley, Molix, Schlegel, & Westgate, 2008), communication difficulties (Edwards, 2005), perceived lack of training (Addington-Hall & O'Callaghan, 2009) and patients' experiences, will determine whether they experience their work as satisfying or stressful. Considering how complex and demanding the delivery of cancer treatment can be, especially in a developing country such as South Africa, it raises the question how do healthcare professionals providing cancer treatment experience working in oncology?

According to Stedman (2005), 'experience' is the involvement in what is happening. 'Experience' is the feeling of emotions and sensations and thus incorporates the sum of a person's perceptions, feelings and memories. Sperry, Griffith, and Powers (2009), are of opinion that patients' illness perceptions are largely derived from their lifestyle convictions. Lifestyle convictions are core schemas or underlying beliefs patients have about themselves, the world, others, and the way things ought to be. Illness perceptions are not only believed to determine treatment outcomes but also to be predictive of treatment compliance (Horne, Weinman, & Hankins, 1998). Illness perceptions consist of a variety of interrelated beliefs about an illness, as well as the perceived effect it is going to have on a patient's life. Major components include: causes, consequences, duration, management of the illness, as well as treatment outcomes (Petrie & Weinman, 2012; Sperry et al. 2009). Illness perceptions are thus the subjective experience of an objective medical condition (Sperry et al. 2009). Patients' subjective experiences may provide important information about underlying processes and can differ significantly from objective interpretations by outside observers (Flanagan, Davidson, & Strauss, 2010).

Treatment outcomes thus depend on more than having a competent physician. Healthcare professionals can provide world-class care, but if the treatment does not correspond with the patient's view of their illness they are likely not to experience it as such and will probably default treatment (Nauert, 2012). Addressing underlying lifestyle convictions (Sperry et al. 2009) and understanding and incorporating illness perceptions into healthcare are thus crucial if treatment outcomes are to be improved (Petrie & Weinman, 2012).

## Research Aims

The general aim of the study was to explore South African cancer patients and healthcare professionals' perceptions and experiences of cancer treatment by comparing the private and public healthcare sectors. The thesis consists of three sub-studies presented in three articles.

The aim of the first article was to provide a narrative literature review exploring cancer survivorship and management in the South African context. The aim of the second article was to quantitatively and qualitatively explore South African cancer patients' perceptions and experiences of cancer treatment by comparing the public and private healthcare sectors. The aim of the third article was to qualitatively explore South African healthcare professionals' perceptions and experiences of working in oncology by comparing the private and public healthcare sectors. All three articles have been submitted to the *Journal of Psychology in Africa*. The first article was published successfully and articles two and three are currently under review.

## Research Questions

The data gathered were used to answer the following research questions:

1. What is known about cancer treatment experiences within a South African context?
2. How do South African cancer patients perceive/experience cancer treatment by comparing the private and public healthcare sectors?
3. How do South African healthcare professionals perceive/experience working in an oncology setting by comparing the private and public healthcare sectors?

## Theoretical Argument

Exploring the perceptions and experiences of both the patients and the healthcare professionals within the same setting will provide a unique opportunity to highlight the similarities and discrepancies stemming from their differing viewpoints. Discrepancies between the identified healthcare preferences of cancer patients and those of the oncology healthcare professionals delivering their care can provide significant information for the development of treatment policies and the educational needs of professionals on how best to meet patients' needs. Comparing the private and public healthcare sectors will further enable us to produce a qualitative description that truly reflects the different realities encompassing cancer treatment in South Africa, where different socioeconomic circumstances often result in very different treatment experiences.

## Methodology

### Design

A mixed-method survey research design was followed by making use of triangulation of measures and different data-analysing techniques. The study consisted of three sub-studies, presented in three articles, each of which is based on one of the three research questions. The first article comprises a narrative literature review highlighting cancer management in the South African context. The second article qualitatively and quantitatively explores cancer patients' perceptions and experiences of cancer treatment as experienced within the private and public healthcare sectors, respectively. The third article provides a qualitative description of healthcare professionals' perceptions and experiences of working in oncology within the private and public healthcare sectors, respectively. These approaches are discussed in more detail in each of the articles presented in chapter two, three and four.

### Participants

Sub-study one consisted of a literature review and, therefore, required no participants. In sub-study two 60 participants were purposively sampled from a private treatment facility (n = 30 patients) and a government-funded hospital (n = 30 patients) in the Eastern Cape, South Africa. The same hospital and private treatment facility was used to purposively sample 40 healthcare professionals (n = 18 participants from the private treatment facility; n = 22 participants from the government-funded hospital) for the third sub-study. Participant characteristics with regard to gender, age, ethnicity and language will be discussed in detail within each of the presented articles.

### Data-gathering methods

For research question one a narrative literature review was undertaken by exploring recent literature captured on various electronic databases such as AtoZ journal list, EbscoHost, Google Scholar, Sabinet Reference, SAePublications, ScienceDirect, and the World Wide Web.

For research question two data was collected by making use of a self-report open-ended questionnaire (chapter 3, addendum 1), interviews, and the Needs Evaluation Questionnaire (chapter 3, addendum 2). For research question three data was collected by making use of a self-report open-ended questionnaire (chapter 4, addendum 1). Although conducting individual interviews during this sub-study was considered, it was decided that, in light of the participating healthcare professionals' workload and the rich data already obtained from the questionnaires, it would be neither practical, nor necessary for data saturation to be reached.

The questionnaires were made available in both Afrikaans and English. Participants were allowed to complete either, based on personal preference. Interviews were also conducted in the participant's language of choice. While the researcher conducted the majority of the interviews independently she was assisted by a qualified social worker and professional nurse, acting as interpreters, in the cases where patients were only able to speak Xhosa.

The above-mentioned measures used will be discussed in more detail in each of the articles, as presented in subsequent chapters.

## Data analysis

Research question one was undertaken by conducting a narrative literature review. Recent literature was critically explored, systematically categorised and integrated in an attempt to reflect on how cancer treatment is experienced within a South African context. For research question two a qualitative content analysis was conducted on the data gathered by the self-report open-ended questionnaire and the interviews. Data gathered by the Needs Evaluation Questionnaire were statistically analysed with the assistance of the Statistical Consultation Services of the North-West University (Potchefstroom Campus). Data gathered for research question three were also analysed by making use of qualitative content analysis.

The methods mentioned above will be discussed in detail in each of the relevant articles presented in subsequent chapters.

## Procedure

Following a review of available literature two self-report open-ended questionnaires were developed, one for cancer patients and one for healthcare professionals, respectively. A pilot study was conducted to ensure that the presented questions were clear and adequately covered the field of cancer treatment. Permission to conduct the study was obtained from the participating organisations (private treatment facility and a government-funded hospital). Participants were approached at their respective treatment centres and informed about the study and its voluntary nature. Informed consent was obtained from all participants.

Questionnaires were handed out at the treatment centres and the interviews scheduled at participants' convenience. Interpreters assisted with the gathering of data from Xhosa participants.

The data gathered consisted of 100 self-report questionnaires, 60 Needs Evaluation Questionnaires, and 36 interviews. The data gathered was then analysed and presented in article format with each article addressing one of the research questions.

### Ethical considerations

Ethical approval was obtained from the ethics committee of the North-West University (Potchefstroom Campus). Informed consent was provided by all participants, each of whom also signed a release form giving permission for the research findings to be published. Confidentiality and anonymity were ensured during the reporting of the results. In an attempt to minimise possible bias, there was continuous corroboration between the authors during every phase of the study.

## Projection of the study

**Chapter two** contains article 1, based on research question 1, and thus presents a narrative literature review focusing on cancer treatment within a South African context. This article explores cancer survivorship and management in the South African context, focusing on: (a) aspects of care/treatment in urban and rural areas and in the private and public healthcare systems, (b) patients needs and psychological care, (c) communication, as well as (d) the influence of religious beliefs on the cancer experience and treatment.

**Chapter three** contains article 2, based on research question 2. This article qualitatively and quantitatively explores cancer patients' perceptions and experiences of cancer treatment by comparing the private and public healthcare sectors in the Eastern Cape, South Africa.

**Chapter four** contains article 3, based on research question 3. This article qualitatively explores healthcare professionals' perceptions and experiences of working in an oncology setting by comparing the private and public healthcare sectors in the Eastern Cape, South Africa.

**Chapter five** provides conclusions, limitations and recommendations based on the integration of the results obtained within each sub-study. Limitations and how these could be considered as detracting from the validity and reliability of the study, as well as the measures used to counter and/or minimise the effects thereof, are highlighted. Recommendations include guidelines with regard to the improvement of treatment, as well as suggestions for future research.

# Chapter 2: Article 1

## Manuscript: Cancer treatment in South Africa: A narrative literature review.

## Abstract

Due to the advances in cancer treatment, there are a growing number of cancer survivors. Finishing treatment rarely indicates the end of the cancer experience. As a result, cancer management has shifted from an acute care model to one that focuses on chronic care issues with a wellness component. This article explores cancer survivorship and management in the South African context, including (a) aspects of care/treatment in urban and rural areas and in the public and private healthcare systems; (b) patient needs and psychological care; (c) communication and healthcare, and (d) the influence of religious beliefs on the cancer experience and treatment. Survivorship is recognised as a distinct phase in the cancer care continuum during which some patients may experience physical and psychological symptoms requiring observation, follow-up, and medical interventions. It is thus critical that chronic care models delivering long-term medical and psychosocial services be developed and utilised. Accessible and equitable screening programmes and individualised cancer care for patients from all socioeconomic groups extending beyond the physical management of their disease are, therefore, something to be strived for.

**Keywords:** cancer patients, care/treatment, urban, rural, public sector, private sector, culture, South Africa

Cancer is a very complex, life-threatening disease affecting millions of people worldwide. Statistics show 1 in 8 deaths worldwide are due to cancer. Worldwide, more deaths are caused by cancer than by AIDS, tuberculosis, and malaria collectively. Cancer is the second leading cause of death in economically developed countries (following heart disease) and the third leading cause of death in developing countries (following heart disease and diarrhoeal diseases) (Garcia et al. 2007). Specifically for developed countries, 1 in 4 deaths in the United States (Siegel, Naishadham, & Jemal, 2012), and more than 1 in 4 (28%) deaths in the United Kingdom can be attributed to cancer (Cancer Research UK, 2011). According to Garcia et al. (2007), there were 12 332 300 estimated new cancer cases worldwide in 2007, of which 78 100 were estimated to be in Southern Africa. The most common types of new cancer cases diagnosed in Southern Africa were cervix uteri (11.8%), breast (10.1%), prostate (8,1%), and Kaposi Sarcoma (6,3%) (Garcia et al. 2007). Kaposi Sarcoma, as the fourth most common cancer site and cause of death in Southern Africa, appears to be more indicative of this particular area than to developing countries in general. Kaposi Sarcoma is a cancer of cells that line lymph and blood vessels and is atypical in that, unlike most other types of cancers, it is multifocal in origin, growing in numerous areas of the body simultaneously (Jemal et al. 2011). In most areas of the world Kaposi Sarcoma is considered an extremely rare type of cancer. It is however frequently diagnosed in Eastern, Middle and Southern Africa due to the high prevalence of HIV found in these regions. Kaposi Sarcoma is considered a main characteristic of AIDS and was one of the first clinical signs to be reported of HIV infection (Cancer Research UK, 2005).

Cancer is not a single disease, but rather an umbrella term used to describe more than a hundred different diseases involving the uncontrolled growth and spread of abnormal cells (Garcia et al. 2007). If this dividing of cells is not stopped, it can spread throughout the body through the lymphatic system or the blood stream (CANSA, 2012). Cancer can involve any tissue of the body and has many different forms in each body area. Most cancers are named according to the type of cell or organ in which they originate (National Cancer Institute, 2012).

### Prevalence

Data collection, compilation, and dissemination are an extremely labour intensive and time-consuming process. It is thus not uncommon for the most recent year for which incidence and mortality data are available to lag up to 3 or 4 years behind the current year (Siegel et al. 2012). The most recent data available, reflecting global cancer statistics, is for the years 2007 and 2008. Of importance, the data categorises South Africa as being a part of Southern Africa and the statistics reported can, therefore, not necessarily be considered as reflective of South Africa per se. Some of the statistics available only differentiate between developed and developing countries, once again not providing data that are truly country-specific. The region classified as being representative of Southern Africa includes Botswana, Lesotho, Namibia, South Africa and Swaziland (Garcia et al. 2007; Jemal et al. 2011).

Prostate cancer in males and breast cancer in females were reported as most frequently diagnosed in developed countries, while breast cancer in females and lung cancer in males were the most commonly diagnosed in developing countries (Jemal et al. 2011; Garcia et al. 2007). Incidence data for the above-mentioned statistics were derived from population-based cancer registries. Cancer registries typically cover smaller, sub-national areas and particularly only urban environments, such as major cities, especially in developing countries. Despite the fact that the quality of information from most of the developing countries is considered as being of limited quality, possibly underestimating the true cancer incidence, it presents the only available profile of cancer and as such provides valuable information (Jemal et al. 2011).

### South African Cancer Statistics

According to the National Cancer Registry of South Africa (National Institute for Occupational Health, 2013), 25 678 new cancer cases were diagnosed in males and 27 205 new cases in females in the year 2005. The majority of these cases were diagnosed in patients between 60 - 69 years of age. This trend tends to be similar to that of the United Kingdom where 75% of cancer cases diagnosed were in people aged 60 years and older (Cancer Research UK, 2011). The three most prominent sites diagnosed in 2005 in South Africa were basal cell carcinoma, prostate and squamous cell carcinoma of the skin in males, while the most prominent sites diagnosed in females included breast, cancer of the cervix, and basal cell carcinoma (National Institute for Occupational Health, 2013).

There also appears to be racial and gender disparities in cancer diagnoses. The most common types of cancer diagnosed in the different racial groups in South Africa were: prostate in Asian males, breast in Asian females, prostate in Black males, cervix in Black females, basal cell carcinoma in Coloured males, breast in Coloured females, and basal cell carcinoma in both White males and females (National Institute for Occupational Health, 2013).

## Patient Needs and Psychological Care

A cancer diagnosis, as well as the experience of cancer treatment can be distressing with common psychological reactions being anxiety, anger, depression and denial (Constantini et al. 1999). Concerns about life-expectancy, quality of life, impact on the family, finances, body image, and pain are but some of the factors generating varying levels of anxiety in cancer patients (Pillay, 2001). Anxiety is likely to negatively affect patients' functioning at a time when they are required to make important decisions about their health. Prolonged anxiety can also have an immunosuppressive effect that may exercise a negative impact on the course of an illness (Linde & Stuart, 2002).

According to Fukui, Koike, Ooba, and Uchitomi (2003) numerous investigators have described cancer patients as having various concerns, including intrapsychic (e.g., anger, fear of dying), interpersonal (e.g., loneliness, communication with family and friends), and social concerns (e.g., isolation and stigmatisation). More than 50% of cancer patients develop significant psychological problems and, therefore, augmenting medical treatment with psychotherapy is likely to enhance quality and possibly even duration of life (Schell, 1999). Even though psychological problems are common and treatable in cancer patients, they are often undetected and not referred for mental health intervention (Fallowfield, Ratcliffe, Jenkins, & Saul, 2001; Pillay, 2001). Cancer patients are at risk for suicidal behaviour and should, therefore, be identified and referred in a timely manner for psychological intervention focusing on helping them cope adequately with their disease and the treatment thereof (Noor-Mahomed, Schlebusch, & Bosch, 2003).

The inclusion of a psychological component to the treatment regime for the alleviation of physical symptoms can often be advantageous to overall improvement. The most prominent physical symptoms and side-effects experienced by cancer patients, as reported by Venter, Venter, Botha, and Strydom (2008), included nausea, fatigue, pain, lack of appetite and hair loss. According to Porter et al. (2002), up to 80% of patients with advanced cancer report experiencing significant pain. Pain and symptom control is, therefore, essential in optimising comfort and quality of life for cancer patients. The key to symptom control is to understand that symptoms are multidimensional perceptions expressed by patients, which are subjective and influenced by physical, emotional, psychological, social and spiritual factors. Therefore, flexibility regarding modes of treatment is the key to treating cancer patients successfully as symptom management extends far beyond the physical (Kraus & Botha, 2007). Unfortunately, perceived inability to deal with the psychosocial needs of cancer patients, time constraints and insufficient training regarding the treatment of terminally ill patients may lead healthcare professionals to focus more on physical rather than psychosocial care (Addington-Hall & O'Callaghan, 2009).

### Holistic Chronic Care Needs

Due to progressive treatments, early detection, and supportive care, we are left with a growing number of cancer patients living well beyond their initial diagnosis and treatment (Rowland & Yancik, 2006). This rising number of cancer survivors highlights the necessity to concentrate on their unique needs, as finishing treatment rarely indicates the end of the cancer experience (Miller, 2008). Survivorship is recognised as a distinct phase in the cancer care continuum during which physical and psychological symptoms, requiring observation, follow-up, and medical interventions, may still be experienced (Goytia et al. 2009). The development of a cancer survivorship identity is, therefore, important. The process of establishing an identity, which includes the concept of cancer, is not a simple process and is often underestimated by the medical professionals when treating cancer patients (Greeff, 2008).

The adjustment to cancer survivorship is a complex and lifelong process (Naus, Ishler, Parrott, & Kovacs, 2009). Not only has the number of treatment choices increased, along with the associated cost thereof (Wilson, 2009), but also the awareness of the necessity to balance experiential versus professional knowledge of cancer during the treatment process (Carlsson, Segesten, Nilbert, & Nilsson, 2007). Benjamin (1995) describes this process as 'combining the will of the patient with the skill of the physician' in the fight against cancer.

In the United States, patient-centred care was identified by the Institute of Medicine (IOM) as being one of the main goals of a high quality healthcare system (Arora, Street, Epstein, & Butow, 2009). Patient-centredness underlines the concept of a healthcare delivery system that treats the "whole" patient instead of only treating the disease (Doyle, Hanks, Cherny, & Calman, 2005; Masalla, De Waal, & Friedrich-Nel, 2010), by focusing on his/her medical as well as psychological needs (Arora et al. 2009). It is a well-known fact that cancer is associated with physical, behavioural, and psychological responses which are influenced by a person's cultural background, stage of disease, age, and marital status (Lo Castro & Schlebusch, 2006; Venter et al. 2008). Psychological and social measures, together with physiological parameters, should, therefore, be used to evaluate and treat patients (Cooperberg, Lubeck, Meng, Mehta, & Carroll, 2004).

In spite of the evidence suggesting biopsychosocial care as being the best way to treat patients, in South Africa, the implementation of this strategy is lacking (Pillay, 2001).

Internationally, there is a large body of psycho-oncology professionals providing specialist services to cancer patients. However, in South Africa there are only a few mental health professionals with a specific interest in cancer care, with even fewer working exclusively in an oncology setting (Manicom, 2010).

### Treatment Research

Despite the above-mentioned need for a biopsychosocial approach, there appears to be limited literature available on the psychological adjustment of cancer patients in South Africa. There is even less literature on cancer patients and healthcare professionals' perceptions of cancer treatment within the South African context. According to Selman et al. (2011), research in Africa has mainly focused on opioid availability and biomedical aspects of cancer, showing a preference for the assessment of physical symptoms, while neglecting psychosocial aspects and holistic care. A bibliometric analysis of research publications funded partially by the Cancer Association of South Africa (CANSA), during 1994 - 2003, found that the majority of the studies focused on the biomedical aspects of cancer, while only 16% of the studies conducted during this timeframe focused on psychosocial factors, such as coping with cancer, prevention, epidemiology and health promotion (Albrecht, 2009).

The greater part of the research accessed by the researcher focused primarily on medical procedures, screening measures and physical concepts related to cancer and cancer treatment. A large number of the articles also appear to be treatment guidelines based on literature reviews of international studies and are not based on research conducted with South African patients treated within a South African environment. Although the content and principles discussed in these articles are worth considering, they do not take into account South Africa's socio-cultural diversity and how these factors can influence the cancer experience and treatment.

### Cultural Factors and Racial Disparities

Cultural beliefs, lack of knowledge and socio-economic circumstances have been linked to patients' reluctance to address health problems by accessing medical care (Lannin et al. 1998). The cause and management of an illness is often conceptualised within a cultural framework. Cultural beliefs thus directly influence patients' health seeking decisions (Wright, 1997). Acknowledgement of cultural and ethnic influences is considered important in the early detection of cancer (Matsheta & Mulaudzi, 2008). A study conducted by Mdondolo, De Villiers, and Ehlers (2003) revealed that some patients believed the cause of cancer to be embedded in the supernatural (ancestral dissatisfaction), witchcraft (sorcery) and other people's jealousy (social dissonance).

A patient's perception regarding the cause of his/her illness can greatly influence his/her decision on whom to consult in terms of healthcare. This perception, coupled with the fact that traditional healers tend to be more accessible and provide culturally congruent care means that they are frequently the first port of call (Mdondolo et al. 2003; Matsheta & Mulaudzi, 2008). Medical treatment is often only sought once traditional remedies prove to be ineffective, and by this time the cancer has often progressed to advanced stages resulting in poor prognoses and poor treatment outcomes (Mullin et al. 2000; Mdondolo et al. 2003).

A study conducted by Matsheta and Mulaudzi (2008), found that there were many similarities between Traditional and Western healthcare professionals with regard to naming the disease, identifying causes, recognising symptoms and diagnostic measures with regard to cervical cancer. Traditional healers should be seen as playing a crucial role in the delivery of healthcare, as they are respected and trusted within the community for their expertise in providing holistic care, and can be of particular value in rural areas where access to biomedical care is limited (Matsheta & Mulaudzi, 2008). While traditional healers are often patients' first port of call when seeking to cure the cause of their illness (i.e. supernatural forces, ancestors, sorcery, or contagion), medical treatment is often only utilised as symptom control (Mtalane, Uys, & Preston-Whyte, 1993). Cooperation between modern healthcare practitioners and traditional healers may, therefore, assist in early detection and treatment, and by doing so improve the mortality rate and quality of care (Matsheta & Mulaudzi, 2008).

The multi-ethnic nature of South Africa's population presents an opportunity to compare disease patterns among different ethnic- or racial groups stemming from the same geographical area. A study conducted by Heyns, Fisher, Lecuona, and Van der Merwe (2011), on comparing the presenting features and management of prostate cancer among different racial groups in the Western Cape found that Black men were less likely to accept potentially curative treatment than Coloured and White men. Among those presented with a potentially curative treatment option, this was chosen by only one-third of Black men, compared to two-thirds of White and Coloured men (Heyns et al. 2011). This is especially concerning as the National Cancer Registry of South Africa's 2005 Incidence Report stated that prostate cancer is the type of cancer most frequently diagnosed in Black men (National Institute for Occupational Health, 2013).

Racial disparity in cancer survival is also reported as being prevalent in the United States. Compared with Whites, African-Americans have less chance of survival once diagnosed with cancer. According to Siegel et al. (2012), African-American patients have a lower 5-year relative survival rate than White patients for all types of cancer at each stage of diagnosis. Unlike the above- mentioned study (Heyns et al. 2011), these disparities were not a result of personal choice but rather from inequalities in access to and receipt of quality healthcare (Siegel et al. 2012). The result, however, remains the same, in that black South Africans and African-Americans are both less likely than Whites to be diagnosed with cancer at a localised stage, when the disease may be more easily and successfully treated. This racially based lack of access to adequate medical care appears to be true in some areas of South Africa as well. Heywood (2002) states that even in ‘post-apartheid’ South Africa, it is still predominantly White people who have access to advanced medical care, while those who only have access to substandard care are primarily Black. This awareness of inequity in access is supported by Smit, Beksinska, Ramkissoon, Kunene, and Penn-Kekana (2004), who reported that in South Africa, over 90% of White women, had accessed cervical cancer screening in the past 10 years compared to only 5% of African women.

## Urban and Rural Cancer Care Disparities

As previously stated, treatment inequality is not always a matter of choice. Factors that can contribute to regional differences in the quality of treatment include differential access to healthcare services, level of awareness/education regarding health conditions and treatment, as well as socio-economic circumstances. There are significant demographic and geographic differences in the utilisation of cancer-screening tests as the availability of screening services, especially for the invasive and more resource intensive-tests, differ considerably from urban to rural areas (Ko, Kreuter, & Baldwin, 2005).

**Quality of care provider.** The management of multifaceted diseases, such as cancer, requires highly specialised professionals, equipment and services (Mathews, West, & Buehler, 2009). It is believed that urban and rural differences in health outcomes may exist due to differences in access, availability and delivery of advanced healthcare resources. Rural residents may be more likely to experience delays in receiving treatment once symptomatic, which may negatively influence their survival (Shugarman et al. 2008).

As previously stated, it is not merely the quality of treatment once diagnosed that can influence prognosis but early detection as well. The utilisation and availability of cancer screening tests are, therefore, fundamental in providing adequate cancer care. A study conducted by Van Schalkwyk, Maree, and Wright (2008), unfortunately found that patients are often mismanaged by healthcare professionals as their lack of knowledge and awareness of cancer often result in low suspicion and thus misdiagnosis. The average number of months from first consulting with a healthcare professional until a diagnosis has been reached ranged from 11.8 months for urban patients to 28.4 months for rural patients. Once diagnosed it took a further three to seven months for treatment to commence (Van Schalkwyk et al. 2008).

The utilisation of services is not determined by availability only. A study conducted by Pillay (2002) on rural and urban South African women's awareness of cancers of the breast and cervix found that over one-third of the women participating in the study were unaware that medical tests could indeed be conducted to detect cancer. It, therefore, appears that the discrepancy between rates of incidence and mortality is likely paralleled in a similar discrepancy regarding education and knowledge, and uptake of cancer screening and treatment.

**Infrastructural resources.** Screening programmes can be effectual provided that they are well-organised and implemented correctly (Sankaranarayanan, Budukh, & Rajkumar, 2000; Gaym et al. 2007; Moodley, 2009). In South Africa, effective screening is not always the case. In 2000, a national screening programme for cervical cancer was introduced (Department of Health, 2000), as well as a screening protocol for regions with limited resources, as recommended by the World Health Organisation (Smith, Moodley, & Hoffman, 2003). A study conducted by Sibiya and Grainger (2007) indicated that rural clinics have insufficient resources and thus struggles to implement the programme successfully. Areas of difficulty include patient follow-up, lack of feedback from referral hospitals and inadequate mechanisms of record keeping. These difficulties are also mentioned by Pillay (2002), who describes the healthcare infrastructure in rural areas as being grossly underdeveloped, and by Statistics South Africa (2000), that reports healthcare facilities for the poor, especially in rural areas, as being insufficient.

Socioeconomic factors can also have an impact on screening practices (Krombein & De Villiers, 2006). This view is supported by Mulaudzi (2003) who states that in rural areas factors such as poor socioeconomic circumstances, inaccessibility of health services, transport problems and widespread poverty, negatively influence early diagnosis of diseases. A study conducted by Mathews et al. (2009), on the factors influencing the treatment decisions of urban and rural cancer patients, found that rural patients were more likely than their urban counterparts to take costs associated with travel, drugs and child care into consideration when making treatment-related decisions.

**Personal factors.** Bettencourt, Talley, Molix, Schlegel, and Westgate's (2008) study on the moderating influence of rural residence on the associations between health locus of control beliefs and psychological well-being, found that while an internal locus of control was imperative to the psychological well-being of urban breast cancer patients, rural patients were found to experience psychological benefits in perceiving powerful others (i.e., healthcare professionals) as having control over their health. Patients' perceptions regarding the quality of treatment provided by healthcare professionals often differ from person to person and can be influenced by the availability of resources and, therefore, the environment within which the healthcare professional operates.

### Public Versus Private Healthcare

A major problem in both the public and private healthcare sectors is often a severe shortage of staff which frequently leads to feelings of frustration in both patient and professional alike. For instance, in 2007 the nurse-to-patient ratio in South Africa's public healthcare sector was reported as being 1:50, while it was 1:3 in the private healthcare sector (Maree & Wright, 2008). Due to this shortage of staff, the resources needed to cope successfully with the demands of the oncology environment are often not available.

Disillusionment regarding the public sector, where poor quality and long waiting times exist, has resulted in an increase in the utilisation of healthcare services in the private sector (Bradley, Risi, & Denny, 2004). According to Bateman (2011), the screening and treatment access gulf between the private- and public healthcare sectors can clearly be seen in the greatly differing treatment routes and outcomes. While private sector patients have access to information, social workers, and support groups, those in the public sector face life-threatening waiting times and a lack of empathy by public sector staff burdened by large patient numbers and a lack of resources (Pillay, 2002; Bateman, 2011). Furthermore, practising preventative healthcare in the public sector is extremely difficult as their daily routine simply does not allow for any kind of cancer screening (Bateman, 2011). Public sector patients are, therefore, more likely to only be diagnosed at advanced stages of cancer, which can negatively influence their treatment outcome.

### Models of Care

The delivery of cancer care has not evolved to reflect the new realities of cancer survival and treatment complexity. The intricacy of the three modalities of cancer treatment (medical, surgical, and radiation), as well as the sheer number of healthcare professionals and tests involved in determining and monitoring treatment regimes, significantly influence the operational structure and outcomes of care (Lee, Fitzgerald, Downey, & Moore, 2012). Even though evidence based research is constantly improving cancer treatments, the implementation of these advances proves challenging as little is known about the ideal model of care for oncology settings. Although a collaborative multi-professional team approach focusing on patient-centred care is promoted by almost all models of care, no specific guidelines or steps are provided on how this is to be accomplished (Lee et al. 2012). It should however, also be noted that despite the fact that collaborative multi-professional teamwork is internationally recognised as an ideal model of care, there is scarcely any empirical evidence demonstrating its effectiveness on patient and organisational outcomes (McCullough, McKinlay, Barthow, Moss, & Wise, 2010, Lee et al. 2012).

## Communication and Information

According to Royak-Schaler et al. (2006), satisfaction with cancer care is frequently associated with the perceived quality of communication among patients, family members and healthcare professionals. According to Epstein and Street (2007), patient-centred communication consists of six key functions that interact to produce optimal patient health outcomes, namely (1) fostering healing relationships, (2) exchanging information, (3) responding to emotions, (4) making decisions, (5) managing uncertainty and (6) enabling patient self-management, which also includes facilitating patient navigation and patient empowerment.

The communication between healthcare professionals and cancer patients has a huge influence on the way in which patients interpret, make decisions about, and cope with their illness (Thorne, Hislop, Kuo, & Armstrong, 2006). Empathic responses made by physicians were found to be particularly beneficial to patients during diagnosis and early in the treatment process as this reduced anxiety (Linde & Stuart, 2002). However, a study conducted by Pollak et al. (2007), found that the oncologists participating in their study only made use of empathic responses in 11% of their conversations.

**Influence of perceived agendas.** According to a study done by Thorne et al. (2006), difficulties with regard to cancer care communications often arise from perceived discrepancies between the agendas of cancer patients and those of the healthcare professional. Patients' communication agendas are believed to include: feeling informed, making informed decisions, managing anxiety, controlling distress and finding hope, while the agendas held by healthcare professionals include: obtaining informed consent, guiding decisions, promoting efficiency, minimising unpleasantness and managing hope (Thorne et al. 2006). Counselling of patients should not be limited to gaining informed consent from patients, but should rather be seen as a continuous process of communication and counselling seeking to address patient fears and anxieties, and to maintain a positive attitude towards treatment (Masalla et al. 2010).

**Patient education.** Patients already bewildered by a diagnosis of cancer may turn to the internet in their search for information and can end up feeling even more lost and confused. A vast amount of information on cancer can be accessed on the internet. It should however be noted that the information presented on some websites may be driven by financial incentive rather than by scientific proof. This could potentially leave patients with unrealistic expectations of certain products or procedures based on misinformation (Heyns & Van Der Merwe, 2008). Healthcare professionals need to realise that patients' informational needs may change over time. Providing information should thus be seen as a continuous process throughout the course of treatment (Fourie, 2010). Bertram and Magnussen (2008), suggest that the presence of a knowledge deficit not only has an impact on the patients' ability to cope with their diagnosis, but also reduces the probability of adherence to treatment plans.

Informational needs can differ from patient to patient (Mullin et al. 2000; Venter et al. 2008). Curtis et al. (2008), report that while some patients are able to receive information in a straightforward manner, others are unable to cope with such an approach. An individualised approach to communication, matching the needs of each patient and his or her family, is, therefore, needed. According to Ogden (2004), effective communication involves the transfer of knowledge from healthcare professionals to patients, which then increases patients' understanding of their illness and consequently compliance to treatment regimes. It is, therefore, very important to inform patients and their families about different treatment options, as well as possible advantages and disadvantages in an unbiased way. Of equal importance are allowing patients enough time to decide which treatment option is best suited to them in terms of their personal needs and expectations (Heyns & Van Der Merwe, 2008).

Having too much information or being too well-informed also appears to have an impact on treatment experiences. Urban-based literate patients tend to more easily conceptualise and grasp the information relating to their treatment. It was found that patients who were better informed about adverse effects expected to experience adverse effects themselves. These patients are more likely to react to even the smallest hint of what they anticipated, based on preconceived expectations and information at their disposal (Masalla et al. 2010).

**Language influence.** In South Africa, language in itself can be an issue when it comes to providing cancer care. As a country with 11 official languages and vast illiteracy, creating effective healthcare campaigns remains a challenge. In poverty-stricken rural areas, illiteracy and a lack of access to other sources of information, such as the internet or television, often means that the contact with healthcare professionals is patients' only opportunity for gaining information regarding their condition. The presence of a language barrier is a daily reality in many treatment environments. For this reason, healthcare professionals and patients are often unable to communicate directly due to a lack of qualified interpreters. Shortage of staff and the high turnover of patients also mean that even with some kind of interpreting service available, many professionals simply do not have the time to inform patients of more than what is absolutely necessary to commence treatment.

**End-stage issues.** Problems with communication are not always related to language. Healthcare professionals often experience difficulty in discussing end-of-life topics and some may even feel that it is not their responsibility (Edwards, 2005; Schulman-Green, McCorkle, Cherlin, Johnson-Hurzeler, & Bradley, 2005; Wilson, 2009). One of the reasons for this might be the fact that an oncologist can seldom be sure about the exact timeframe involved when patients are nearing the end of life (Voorhees et al. 2009; Wilson, 2009). Factors such as preserving hope, not wanting to be the bearer of bad news, as well as the desire to remain optimistic, are reported as fundamental reasons for the difficulties physicians experience in discussing prognostic information with patients (Voorhees et al. 2009). For many people, hope is experienced within a religious context. Religion provides people with a coherent belief system within which meaning and hope can be found (Seligman, 2002).

## Religious Beliefs

A cancer diagnosis can create an existential crisis in the lives of cancer patients and their families. According to Venter et al. (2008), religion was seen as having an influence on how cancer patients experience their illness. Whereas the medical path usually becomes evident upon the diagnosis of a specific type of cancer, the pastoral path may not be as clear due to the differing responses of cancer patients (Brunsdon & Lotter, 2008). In Venter et al.'s study (2008), some patients reported insensitive referrals to eternal life and experiencing a crisis of faith as having a negative impact on their disease-related experiences, while others viewed religion as not only being an invaluable source of support, but also as providing them with a framework within which to understand their experiences. Ogden (2004), classifies religious beliefs as being one of various coping strategies frequently used by cancer patients, enabling them to make sense of adversities, stresses and inevitable losses (Carr, 2004).

The following six topics were identified by Brunsdon and Lotter (2008), as possible focus areas in the pastoral process: the problem of theodicy, end-of-life counselling, suffering, the relationship between sin and illness, ethical issues of a medical nature, as well as eschatological perspectives. It is clear that the cancer experience extends beyond the physical as negative discourses and the radicalism of treatment necessitate focusing on a variety of crises, which can often include religious and existential aspects. Focusing on the areas suggested by Brunsdon and Lotter (2008) can be potentially valuable as research indicate that cancer patients who use their spiritual and religious convictions to cope with their illness are more likely to accept their illness and employ positive and purposeful coping strategies (Weaver & Flannelly, 2004).

## Conclusion

Cancer is a multifaceted disease requiring multidimensional care provided by a multi-professional team (Mathews et al. 2009). The reality, however, is that patients are often treated in a fragmented outpatient setting where the screening and treatment access gulf between the private and public healthcare sectors can clearly be seen in their greatly differing treatment routes and outcomes (Bateman, 2011). Cancer care is further influenced by various cultural beliefs, as well as by education and knowledge regarding cancer treatment and its prevention (Lannin et al. 1998). Accessible and equitable screening programmes and individualised cancer care for patients from all socioeconomic groups extending beyond the physical management of their disease would be an ideal. In a developing country such as South Africa, this approach remains a challenge due to competing healthcare priorities and poor resources, especially in rural areas (Pillay, 2002).

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# Chapter 3: Article 2

## Manuscript: Patients' experiences of cancer treatment in the private and public healthcare sectors in the Eastern Cape, South Africa.

# Abstract

Regardless of the evidence suggesting biopsychosocial care as being the best way to treat cancer patients, in South Africa the implementation of this strategy appears to be insufficient. The aim of this study was to qualitatively and quantitatively explore cancer patients' perceptions and experiences of cancer treatment by comparing the private and public healthcare sectors in the Eastern Cape, South Africa. A mixed-method survey research design was followed and 60 participants were purposively sampled from a government-funded hospital and a private treatment facility. Qualitative data was collected by a semi-structured self-report questionnaire and semi-structured interviews, while quantitative data was gathered by using the Needs Evaluation Questionnaire (NEQ). Analysis of the qualitative data yielded 12 prevalent themes namely experience of treatment, diagnosis, preconceived ideas, information and communication, treatment decisions, changes resulting from treatment, coping strategies, support system, medical aids, healthcare professionals, research, and changes needed in the treatment process. The majority of the differences regarding treatment experiences between the two groups can be traced back to systemic problems in the public sector due to a lack of technical and human resources. Results obtained by the NEQ were statistically and practically significant and showed patients receiving treatment in the public sector as having more unsatisfied needs than those receiving private healthcare. Government policy addressing the above-mentioned discrepancies needs to be developed and the ones in place need to be better managed and enforced.

**Keywords:** cancer treatment, healthcare, private sector, public sector, government-funded, perceptions, experiences, South Africa

# Introduction

Cancer is a complex disease often associated with a large number of symptoms that is not only associated with the progression of the disease itself, but can also be due to the treatment thereof (Bennion & Molassiotis, 2013). The psychosocial effects of the disease can be treated by making use of various psychological and behavioural interventions focusing on the trauma of realising one has a potentially life-threatening disease; learning more about the disease; confronting difficulties with positive cognitive states; and employing active behavioural strategies (Andersen, 1992).

Worldwide, more deaths are caused by cancer than by AIDS, tuberculosis, and malaria collectively (Garcia et al. 2007). Approximately 12,7 million cancer cases and 7,6 million cancer deaths are projected to have occurred in 2008 worldwide, with 56% of the cases and 64% of the deaths being in the economically developing world (Jemal et al. 2011). This time lapse for the most recent incidence and mortality data is caused by the time required for data collection, compilation and dissemination (Siegel, Naishadham, & Jemal, 2012). The time lapse for available South African cancer statistics appears to be much bigger than that for global cancer statistics as the most recent statistics made available by the National Cancer Registry (NCR) of South Africa are for the year 2005. According to the National Cancer Registry of South Africa (National Institute for Occupational Health, 2013), 25 678 new cancer cases were diagnosed in males and 27 205 new cases in females in the year 2005. The NCR is a pathology-based cancer registry that only receives data from public and private histopathology, cytology and haematology laboratories countrywide (National Health Laboratory Service Annual Report 2008 - 2009). Being a pathology-based registry, the reports generated does not provide a true reflection of the cancer incidence in the country as cancer cases that are not diagnosed in this way are not reported (Singh, 2011).

In the past cancer reporting was not a legal requirement and due to issues pertaining to patient confidentiality in 2001, many private pathology services ceased to submit their data. On 26 April 2011, however, new regulations concerning the registration of cancers were promulgated requiring every healthcare professional who has diagnosed a new case of cancer to report the case on the prescribed form as indicated by the National Health Act, 2003 (Act No 61 of 2003 – Regulations relating to cancer registration No. R. 380)(Government Gazette, No. 34248, 2011; Singh, 2011).

## Challenges in cancer care in South Africa

Due to the progress made in the field of oncology, cancer is no longer seen as a death sentence and is presently regarded as a chronic illness (Greeff, 2008) for which adjustment to survivorship is a complex and life-long process (Naus, Ishler, Parrott, & Kovacs, 2009). The nature of cancer care is becoming progressively more complicated. Regardless of the evidence suggesting biopsychosocial care as being the best way to treat cancer patients, in South Africa, the implementation of this strategy appears to be mostly insufficient (Pillay, 2001). Patient diversity, combined with staff shortages and a lack of necessary resources to deal with the demands of the oncology environment, results in a cancer care delivery system that does not reflect the new realities of cancer survival (Maree & Wright, 2008).

South Africa is often referred to as the “rainbow nation”, a title which illustrates the country’s unusually diverse population (Ribot, Morris, Sealy, & Maggs, 2010). According to Statistics South Africa’s mid-year population estimates (2011), there are 50 586 757 South Africans, of which 79% are African, 9% Coloured, 9% White and 2,5% Indian/Asian. The African population is further divided into a variety of ethnic groups such as Zulu, Xhosa, Basotho, Bapedi, Venda, Tswana, Tsonga, Swazi, and Ndebele, each of which speaks a different African language. It is, therefore, very likely that physician and patient come from different cultural backgrounds influencing their healthcare beliefs and behaviours (Pfaff & Couper, 2009). Although English is generally understood across the country and commonly used in public and commercial life, it is only the fifth most-spoken home language (South Africa Fast Facts, 2007). A further challenge is, therefore, communicating detailed information about diagnoses and treatment regimes, while facing not only a language barrier, but also differing cultural beliefs influencing health perceptions and symptom experiences.

In South Africa primary healthcare is provided by the government with cancer care facilities being only available in the bigger cities, which means that a large number of patients often have to travel long distances in order to access cancer treatment (Lourens, 2013). According to Somdyala, Bradshaw, Gelderblom, and Parkin (2010), only about 20% of the South African population, who has access to and can afford health insurance, are treated within the private healthcare sector. Furthermore, the screening and treatment access gulf between the public and private healthcare sectors is evident in their hugely differing treatment routes and outcomes (Bateman, 2011). Patients are often mismanaged by healthcare professionals (Van Schalkwyk, Maree, & Wright, 2008). Contributing factors to the mismanagement of patients in South Africa include opportunistic and isolated screening, ignorance, apathy, and overworked healthcare professionals (Michelow, McKee, &

Hlongwane, 2006). Apart from the cultural influences and language constraints mentioned, a lack of confidence and insufficient training in dealing with the psychosocial needs of cancer patients often results in healthcare professionals focusing almost exclusively on organic pathology (Pillay 2001; Addington-Hall & O'Callaghan, 2009). This is further exacerbated by ineffective screening (Sibiya & Grainger, 2007), a poor referral system (Van Schalkwyk et al. 2008), and severe staff shortages (Maree & Wright, 2008).

Despite government initiatives the needs still outweighs the resources. Unfortunately, the much-awaited improvement in health services, especially in the rural communities of South Africa, is unlikely to materialise due to the large quantity of patients with AIDS-related illnesses requiring treatment, and the extraordinarily high turnover of patients being treated in the public healthcare sector (Kruger & Apffelstaedt, 2009; Pillay, 2002). Based on the above mentioned it is, therefore, safe to say that the South African healthcare system lacks the resources to deal adequately with the demands of the oncology environment.

A study, previously conducted by the researchers, highlighted cancer patients' perceptions and experiences of treatment as being one of the most prominent themes influencing their overall cancer experience (Venter, Venter, Botha, & Strydom, 2008). According to Ogden (2004), there appears to be a conditioning effect concerning patients' beliefs regarding the effectiveness of interventions and the competence of healthcare professionals. This was also evident in Venter et al.'s (2008) study, as positive perceptions regarding the medical profession and treatment appeared to be associated with the report of more positive illness experiences. This, coupled with the fact that the majority of research studies previously conducted in South Africa generally focused on the biomedical aspects of cancer (Albrecht, 2009), makes exploring South African cancer patients' treatment experiences potentially valuable as the accurate assessment of patients' needs is central to improving adherence to treatment, treatment satisfaction, and quality of life (Annunziata, Muzzatti, & Altoé, 2009). According to Olver, Eliott, Long, McKinnon, and Rumsby (2012), it is also increasingly recognised that the evaluation of patients' experiences provide important information regarding patients' preferences which may prove valuable for developing treatment policies and educating professionals on how best to meet patients' needs.

### Research Aims

The aim of this study was to quantitatively and qualitatively explore South African cancer patients' perceptions and experiences of cancer treatment by comparing the public and private healthcare sectors.

## Method

### Design

A mixed-method survey research design was followed, as this type of design is especially appropriate for research questions about self-reported beliefs (Neuman, 2003). A comparative study regarding the perceptions and experiences of cancer patients, with regard to cancer treatment and needs, receiving treatment within the private and public sector was conducted.

While treatment within the private sector is mostly funded by patients' medical aids and personal funds the public sector is typically government-funded. Patients receiving private healthcare in the private sector are considered private patients while those receiving government-funded treatment within the public sector are considered government patients.

### Participants

Sixty participants were purposively sampled from a government-funded hospital and a private treatment facility in the Eastern Cape. Inclusion criteria included: (1) age above 18 years; (2) having a cancer diagnosis; and (3) currently receiving treatment. Although literacy is usually an important factor for selection, illiteracy was not considered as being a criterion for exclusion, as the vast majority of patients in the public sector are often illiterate.

The private healthcare group consisted of 30 patients, 12 of whom were male and 18 female, ranging from 27 to 71 years in age. Seventeen were White, seven Black, five Coloured, and one Indian. Sixteen identified their home language as Afrikaans, eight as English, and six as being Xhosa.

The public healthcare group consisted of 30 patients, 11 of whom were male and 19 female, ranging from 18 to 73 years in age. Nine were White, 10 Black, and 11 Coloured. Eighteen identified their home language as Afrikaans, two as English and 10 as being Xhosa.

All 60 participants had been diagnosed with different types of cancer and were at various phases in the treatment process. In the private healthcare group 28 participants were receiving active treatment while two indicated being in the follow-up stage of treatment. Twenty-seven of the participants in the public healthcare group were receiving active treatment and three reported being in the follow-up stages of their treatment. It is for this reason that they will be referred to as ‘patients’ during the results discussion.

### Data-gathering methods

The researcher (first author) made use of both qualitative and quantitative measures during data collection. This process of triangulation is believed to produce a more complete picture as measuring something in more than one way increases the likelihood of seeing all aspects of it (Neuman, 2003).

A pilot study was conducted in an attempt to ensure that the questions, selected from the literature to be included in the questionnaire, were clear and adequately covered the field of cancer treatment. This was done by working through each set of questions with two patients and two healthcare professionals.

In an attempt to elicit responses truly reflective of each patient’s experiences, the qualitative methods were employed first and then followed up with quantitative measurement. The reason for this was that the researcher believes that when presented with different options, as is often the case with questionnaires used in quantitative measurement, participants tend to use ‘words’ and ‘phrases’ indicated in the questionnaire when formulating their qualitative answers. This might lead to questions being answered in a more theoretical manner instead of an honest reaction based on personal experiences.

Qualitatively the study was conducted by initially gathering data on a general topic (cancer treatment) and then moved towards adjusting and refining the research questions as important issues and questions emerged based on the preliminary analysis of the data. Participants were asked to complete a semi-structured self-report questionnaire consisting mostly of open-ended questions (addendum 1) regarding their treatment process. Interviews, making use of the same question format, were also conducted.

Quantitative methods included making use of the Needs Evaluation Questionnaire (NEQ) to determine the most prominent needs experienced by the cancer patients (Tamburini et al. 2000). The NEQ is a self-administered questionnaire composed of 23 dichotomous items (addendum 2) allowing for the registration of patients’ most common needs (Tamburini et al. 2000). According to Annuziata et al. (2009), the NEQ consists of five factors which are significantly and positively correlated. The item content of the five factors suggests the existence of five subscales, namely (1) informative needs, (2) needs related to assistance/care, (3) relational needs, (4) needs for psychoemotional support, and (5) material needs. This resulting five-factor model has good levels of internal factor structure validity, thus extending its usefulness from clinical practice to research domains (Annuziata et al. 2009).

All the patients were evaluated at their respective treatment centres. The self-report questionnaire and NEQ were made available in both Afrikaans and English, giving patients the opportunity to decide which version they felt most comfortable with. Twenty-four patients completed the questionnaires independently while 19 government patients and 17 private patients required assistance. The researcher ensured that any assistance provided did not influence patient responses in any way. Assistance consisted of reading the questions presented in the questionnaires to the patients followed by the verbatim recording of their responses. Reasons for not being able to complete the questionnaires independently included language barriers, illiteracy, and physical discomfort due to treatment. Seventeen patients from the private sector and 19 from the public sector were interviewed following the same format as those who completed the questionnaires independently. While the researcher conducted the majority of the interviews, she was assisted by a qualified social worker and professional nurse, acting as interpreters, in the cases where patients were only able to speak Xhosa.

## Data Analysis

The researcher analysed the data gathered by the self-report questionnaire and interviews, by making use of qualitative content analysis. Qualitative content analysis involves the subjective interpretation of the content of text data, employing a systematic classification process which focuses on coding and identifying themes or patterns (Hsieh & Shannon, 2005). The purpose of content analysis is ‘to provide knowledge and understanding of the phenomenon under study’ (Neuman, 2003), which in this case refers to the treatment experiences and perceptions of private and government funded healthcare cancer patients in South Africa.

The researcher started by independently reading the completed questionnaires and interview transcripts as a whole in an attempt to gain a general understanding of what the patients expressed regarding the phenomenon under study. She then moved on to independently condense the text into units of meaning. The extracted items were then discussed by the researcher and two other authors where a final categorisation of items was obtained. Initially the researcher made use of open coding, which involves the process of breaking down, examining, comparing, conceptualising and categorising the data. The data was then put back together by making connections between the different categories. This procedure is called axial coding. Lastly, selective coding was conducted which involved the identification of core categories and how they systematically relate to one another (De Vos, Strydom, Fouchè, & Delport, 2005). By making use of this approach the researcher was able to produce a qualitative description of the cancer patients' views on cancer treatment within a South African context.

The researcher also made use of inferential statistics to test whether the descriptive results are likely to be due to random factors or to a real relationship (Neuman, 2003). A statistical significance test (t-test) was applied to the data collected by the NEQ to determine whether or not the differences between the means for each of the subscales, as previously mentioned, for the public healthcare group's needs and the private healthcare group's needs were significant.

## Trustworthiness

Verification strategies for establishing reliability and validity in qualitative research are employed to ensure the attainment of rigour (Morse, Barrett, Mayan, Olson, & Spiers, 2002). This then demonstrates the trustworthiness of a qualitative research study. To establish trustworthiness in qualitative inquiry, Guba and Lincoln (1989) appealed to the criteria of credibility, transferability, dependability and confirmability. The researcher employed various strategies, as suggested by Shenton (2004), in an attempt to fulfil above-mentioned criteria, which included the following: To ensure credibility the researcher made use of sound research methods, developed an early familiarity with the culture of participating organisations, and examined previous research by conducting a literature review on cancer research conducted in South Africa in order to frame findings. A familiarity with the culture of the participating organisations was obtained through the process of gaining permission to conduct the study. Each organisation had its own requirements and procedural specifications that needed to be adhered to before permission to conduct the study was granted. By providing a comprehensive description of the biographical details of the participants the researcher was able to establish the context of the study. Establishing the context of the study, coupled with a detailed description of the phenomenon in question and providing a sound research design for comparative purposes, allows for transferability. Dependability was achieved by providing an in-depth methodological description of the study, thus allowing for the replication thereof should the need arise. Confirmability was established by making use of triangulation in an attempt to reduce investigator bias. This was done by continuous collaboration between the researchers throughout the research process in an attempt to minimise any possible bias and to ensure that the methods used were employed correctly, as well as to confirm and organise findings.

## Validity and Reliability

As the NEQ was developed and validated in an Italian context, the researcher wanted to determine if the NEQ could be used with a South African sample.

[place figure 1 here]

Confirmatory factor analysis (CFA) was undertaken for testing the validity of the five-factor solution. The structural equation modelling software used included AMOS (Amos Development Company, 2011) and SPSS (SPSS Inc., 2011). All regression weights were statistically significant. Absolute fit indices included the chi-square test, which produced a poor fit ($p<0.001$), but because the chi-square test is often viewed as being overly strict (Hancock & Mueller, 2010), the chi-square test statistic was divided by degrees of freedom as suggested by Mueller (1996), yielding an acceptable value of 1.762. For a tenable model the value should be close to 1, and some interpret ratios as high as 3, 4 or even 5 as still representing a good model fit (Mueller, 1996). According to Hancock and Mueller (2010), it is however considered good practice to report multiple fit indices, typically from three broad classes. A Comparative Fit Index (CFI) value of 0.834 was found. According to Mueller (1996), a CFI above 0.9 is generally indicative of a good overall fit, making the CFI of 0.834 relatively acceptable. A Root Mean Square Error of Approximation (RMSEA) value of 0.114 with a 90% confidence interval of [0.094; 0.133] indicated lack of fit as Blunch (2008), state that models with RMSEA values > 0.10 should not be accepted.

Cronbach's coefficient alpha was used to determine the reliability of the NEQ when used with a South African sample. A Cronbach alpha value larger than 0.7 was found for all five factors which according to Kline (1999), is considered acceptable.

## Ethical Concerns

Approval for the study was obtained from the ethics committee of the North-West University (Potchefstroom Campus) prior to commencement of the study (NWU-00125-11-A1). Participants were informed about the research project and participation was voluntary. Informed consent was obtained from all research participants and relevant organisations prior to data collection. All participants also signed release forms for the use of the data gathered and gave permission for the research findings to be published. Confidentiality and anonymity were maintained by ensuring that no identifiable information was made available during the reporting of the results.

## Results

The themes identified (table 1) are discussed below. Despite a lot of similarities there were also notable differences between patients receiving treatment in the private and public healthcare sectors. The first theme presented provides an overall view of treatment as experienced by the patients. Themes two to eight are subsequently presented to indicate the treatment process as it typically occurs, while themes nine through 11 focus on various aspects arising from the treatment process. Theme 12 concludes with the changes needed in the treatment process, as recommended by the patients' perspectives. In an effort to avoid the unnecessary repetition of overlapping themes, initial themes were discussed extensively and then referred to should certain aspects thereof become relevant in subsequent themes.

[place table 1 here]

### Theme 1: Experience of treatment

The majority of the patients in both groups experienced overall cancer treatment as being a positive experience. The main reason given for this is the fact that it makes them feel proactive as it often brings about change with regard to physical symptoms and cancer scores. This not only provides the patients with physical relief but also gives them hope of being cured. Patients in the private sector reported: *"...can feel a difference…something is changing…"* and *"...grateful for wonderful treatments giving one a second chance at life..."* Public sector patients reported similar experiences by making the following statements: *"I see a lot of changes, I was weak but now I'm strong…"* and *"...feels like I'm doing something...like I'm taking control somehow…"*

Although patients generally had a positive opinion about overall treatment, both groups admitted to it being a challenging experience, with side-effects being viewed as the main problem. The side-effects mentioned by the majority of the patients included pain, fatigue, nausea, hair loss, loss of appetite, mouth and throat sores, and dizziness. Responses included: "*…don't feel like yourself anymore…"; "difficult due to the side effects…"* and *"...painful physically and emotionally…"* While none of the private sector patients reported treatment as being of no benefit, a minority of the public sector group did express feelings of this nature. One of these patients expressed this as follows: *"...sometimes I feel that everything you have to go through isn't really worth it…I don't see any changes…"*

The fact that treatment is time-consuming is repeatedly mentioned by both groups. A distinction with regard to this experience is found in that private sector patients report the actual time spent receiving treatment, for example while chemotherapy is being administered, as being frustrating while public sector patients report long waiting periods, prior to and between treatments, as being the main reason for displeasure. Private sector patients' frustrations then also seem to stem from the fact that the time spent receiving treatment takes away from other commitments that they are then unable to fulfil. One private sector patient explained this as follows: "*…the time that I have to spend sitting here* [receiving chemotherapy] *is challenging. Mostly because all the other things I have to be doing are now at a standstill, but I also realise that if I didn't take the time for treatment I won't be having any 'time' left period…so it's probably an okay trade considering…"* Public sector patients' frustrations with long waiting periods seem to be stemming mainly from lack of resources and poor administration. The following are some of the statements made by public sector patients in this regard: *"…appointments are a farce…appointment was for 08h00, but I often have to wait until late in the afternoon…"; "…takes terribly long before you are helped…try their best but sometimes there are as many as forty-five patients to treat with treatment varying from one to two and a half hours per patient…";* and *"…I acknowledge that staff shortages are mostly to blame for long waits…but would appreciate the filling of posts for doctors…"*

Despite their own struggle with cancer the majority of the patients receiving private healthcare expressed concern and even some guilt feelings about those less fortunate than themselves when it came to quality of care and treatment accessibility. Some of the comments made by these patients included the following: *"…disheartening to know that government patients get the raw end of the deal…worrisome as you don't know if they'll be okay…it's not fair that they need to die just because they don't have medical aid…for example, I know of a patient whose surgery got postponed for two months because of staff shortages…that's not fair…"*; *"…when I think of all the people less privileged than I am…I wish that they could have the same treatment as me…because basically we have the same disease…it's also more than just the actual medication…the way you're being treated is important, as is a positive environment…"* and *"…accessible treatment for everyone…people should not be penalised for not having money…"*

### Theme 2: Diagnosis

Patients from both groups expressed experiencing a delay in being diagnosed correctly. One of the patients receiving treatment within the public sector described the experience as follows: *"…was sent from clinic to hospital, from hospital to clinic…and back to hospital…it took a long time for them to tell me I have cancer…"* This is, however, not a phenomenon only experienced in public healthcare as patients receiving private healthcare reported delayed diagnoses as well: *"It took a long time to get to a correct diagnosis. I was even on T.B. treatment at some stage…"* Both groups described experiencing their diagnoses as being a shock initially. However, knowing what is wrong and how it can be treated provided a sense of relief compared to not knowing what is wrong at all. Patients' accounts of this include: *"…shocked at being told I have cancer…"* and *"…know what is wrong, you can get treatment…"* While public sector patients experienced quick commencement of treatment as being positive, *"…everything happened very fast…appreciate this…makes me feel like something is being done…chance of being cured is better…"*, some private sector patients expressed the need for more time to come to terms with what needs to happen. One patient expressed this as, *"…there should be less haste with regards to treatment…by the time I realised what was happening the operation had already been done and I had already started with treatment…"* Despite this difference in treatment commencement needs both groups clearly expressed a need for earlier diagnoses and more cancer awareness. Statements made included: *"…an attempt should be made to achieve earlier diagnosis…"* and *"…educating general practitioners more about cancer and its diagnosis…"*

### Theme 3: Preconceived ideas

Both groups felt that their initial fears were exacerbated by what other patients had experienced and that it was mainly fear of the unknown and myths about certain treatments that had led to treatment anxiety. Both groups did, however, also indicate that once they had started treatment and had a personal frame of reference to work from they were pleasantly surprised by how well they were able to cope. This phenomenon was expressed as follows: *"…initially I was scared because of all the horror stories one hears…"*; *"…not as frightening as many people led me to believe…"* and *"…main worry was fear of the unknown, once the initial tests, x-rays, ultrasound and bone scan had been done and I've had my first chemo I felt that I could cope…"* Once they were immersed in the treatment process it was not as frightening as they had once believed as each patient's reaction to treatment is unique. Patients from both the public and the private sector indicated the importance of acknowledging each patient's individuality and unique treatment experience. Statements made to this effect included: *"...learned that I was one of a kind and that we all react differently…"* and *"...as patients we need to realise that everyone is different…we cannot compare ourselves with anyone else…"*

### Theme 4: Information and communication

Both groups admitted to having a limited understanding of cancer treatment prior to being diagnosed and starting treatment themselves. *"...initially I didn't really know what was going on…I didn't have many questions though because I didn't know much about cancer so I didn't really know what to ask..."* It was only as the treatment process progressed that informational needs and communication opportunities became an important aspect in navigating the road to potential recovery.

Although patients receiving treatment in the private sector reported being kept well informed about their condition and treatment, a minority, however, admitted to, at times, not understanding said explanations due to medical terminology used. The majority did, however, feel that any terminology used was sufficiently explained. Information was presented to them verbally, as well as in written format with ample opportunity for discussion. An effort also appeared to be made with regard to overcoming potential language barriers between the patients and medical staff. Some of the statements made by these patients included: *"...was kept informed completely…"*; *"...everything was well explained…"*; *"...reading matter…easy to understand and beneficial…"*; *"...medical terms were far 'above me'...difficult to comprehend…"*; *"...used simple terms that I could understand…even made drawings to illustrate…"*; *"...was given time to talk to them during which all my questions were answered…"*; *"... ensured that I understood…they always asked an interpreter to be present during discussions…"* and *"...makes sure that you have a good concept about what is going on…never gave the impression of being in a hurry or working against the clock...made me feel important…"*

Although a minority of the patients in the public sector reported being satisfied with the information presented to them, as well as with the opportunities for communication the majority of the patients felt quite differently. What these patients describe is a situation rife with uncertainty, limited comprehension and poor communication. The following comments were made in this regard: *"...never know what is going on…just send you from one person to the next…information was not satisfactory…"* ; *"...don't really give explanations…use big words…don't really understand…"*; *"...information doesn't differ…feels like they're in a* *routine and then they just tell everybody the same thing…not personal…"*; *"…they always just say 'continue as is and your follow-up is on'…there is no inner compassion that makes you feel like they're really taking notice of you as a person…"* and *"…the doctor doesn't understand me…he talks his own things…"*

Both groups felt that taking a friend or family member along to consultations was beneficial as this person could then help them to understand what the doctor had said.

Patients in the private healthcare group reported having the following needs with regard to information and communication: more dietary information, peer support groups where coping skills may be shared, information on available support groups and workshops, and information that is more case-specific, instead of on cancer in general. Patients in the public sector group reported having a need for better explanations, more detailed information, first-language communication, and honest straight answers. Both groups also felt that educating the community and people in general about cancer is important. While those in the public sector felt the focus should be on the importance of treatment compliance, those in the private healthcare group deemed normalising and expelling myths about cancer as important focus areas.

### Theme 5: Treatment decisions

The private sector patients indicated feeling included and reported being involved in decisions made about their treatment. They did, however, report a tendency to surrender decision making to the healthcare professionals involved stating a lack of medical knowledge and trust in their doctor's ability as their reasons for doing so. A few of the patients explained this as follows: *"…very involved…"*; *"…everything was explained to me step by step…"*; *"…allowed me to participate and make informed choices…"* and *"…comfortable leaving it in the hands of my doctor…knows best and I'm not a doctor so I'm comfortable with letting her take the lead…"*

Although a minority of the public sector patients reported similar experiences to those of the private sector patients, the majority of them reported feeling excluded from the decision-making regarding their treatment process. While some expressed feeling not included yet being comfortable with surrendering to a powerful other, other patients expressed feeling excluded and felt that healthcare professionals were being directive. This differentiation can clearly be seen in the following statements made: *"…I wasn't involved in the decisions, they told me that I had to get chemo and I'm satisfied with that…I suppose they know best…"*; *"…I was excluded, not really consulted in the matter…they tell you what it is* *that you have to do and you just have to do it…"* and *"…they never asked my opinion. I would like for them to sometimes ask my opinion as well instead of only telling me what to do all the time…"*

**Theme 6: Changes resulting from treatment**

While both groups indicated the treatment process to be better than expected, they did, however, also acknowledge that treatment often influences a person's entire life, bringing about various lifestyle changes. One patient described this as: *"…'me before cancer' and 'me after cancer'…"* While both groups indicated the financial burden of treatment, a distinct difference can be found in the effect thereof. While the following statement was made by a patient from the private sector: *"…medication, travel and consultations are expensive…had to do without many things to accommodate financing for cancer treatment…"* those receiving government-funded healthcare painted a much grimmer picture with statements such as: *"…I don't always have the money to get to treatment…"* and *"…borrow money against my children's grant money for taxi-fare…they need a lot of things for school…makes me feel guilty …"*

Change was, however, not limited to financial status as treatment often has far-reaching effects on all aspects of patients' lives. One patient summarised this as: *"…the psycho-social aspects of treatment has to a large extent been more overwhelming than the actual treatment…"* Both groups indicated various lifestyle changes in order to accommodate treatment such as dropping out of school, moving to a different city in order to be closer to familial support, accepting assistance from others when needed, and dietary adjustments.

Some changes were, however, brought about by new perspectives resulting from the cancer experience. Both groups indicated developing a deeper appreciation for life and expressed going through a process of personal growth that not only influenced how they viewed the world but also had a positive impact on their relationships with others. A patient from the private sector described the following experience: *"…learned so much about my body…I now have an improved body image…now know that I am not loved because of my body parts (breasts) or my beauty (hair loss)…this has deepened my relationship with my husband…"*, while one from the public sector said: *"…I was a very different person before I became ill…I've come to realise that everything isn't always about me…I see a lot of things now that I didn't use to see…like the fact that my family is concerned about me…I now acknowledge when other people take an interest in how I'm doing…"*

**Theme 7: Coping strategies**

Various coping strategies were employed by both groups in an attempt to deal with their illness and the treatment thereof. Private sector patients appeared to be using a more metacognitive approach in regulating their emotional states while those in the government-funded healthcare group expressed more accommodating and practical coping strategies. Patients in the private sector expressed the importance of acceptance, placing things in perspective, and cultivating a positive mindset as being key aspects in coping successfully with cancer and the effects of the whole treatment experience. Statements made to this effect include: *"...started to accept what was happening and became more positive…that was when my symptoms started to improve…"* and *"…work from a positive perspective...focus on everything you still have instead of on everything that you have lost…"*

Coping strategies described by patients in the public sector group included finding practical ways to dealing with frustrations such as finding something to occupy yourself with when faced with long waiting times and engaging in as many 'normal' activities as possible. Patients expressed this as follows: *"...know you're going to have to wait a long time so bring stuff which you can keep busy with, like newspapers and books…if you prepare yourself to stay for the whole day...you'll be less frustrated…"* and *"...important to do as may normal things as possible…like going for a walk or spending time with family…it will make you feel better…"*

Both groups also described their religion as providing an invaluable source of support. Having faith was seen as a resource to be drawn upon in difficult times as strength was drawn from their connection with God and was seen as eliciting positive thoughts, which in turn increased their coping abilities. This experience was described as follows: *"…anything can be done if one has faith…"; "…unwavering faith carried me through, I never felt like giving up…"* and *"...best part is knowing that God has the final say…without Him I wouldn't have made it…"*

**Theme 8: Support system**

Although both groups expressed appreciation for support received, a clear difference can be found in their perceptions of how their illness is affecting their support systems. While private healthcare patients focused primarily on how helpful their family members were and how grateful they were for the support provided those receiving public healthcare appeared to be plagued by concern and guilt over the amount of disruption and discomfort their illness is creating within their families. This differentiation can clearly be seen in the following statements regarding support: *"…my family was very supportive, so going through it wasn't that difficult…"* and *"…influences the whole family with regards to practical arrangements like transport, childcare, and tasks that need to be done…family members suffer just as much…"*

### Theme 9: Medical aids

As previously mentioned in the theme 'changes resulting from treatment', the financial impact of cancer treatment can be far-reaching. Although being part of a good medical aid scheme is generally considered as reducing financial stress, worry about its depletion appears to be constantly present. Another belief is that having a good medical aid means access to private treatment, which is generally believed to be superior. Despite access to private sector treatment there is, however, still treatments not covered by medical aids or that require substantial patient contributions as certain private treatment facilities charge more than the amount covered by medical aids.

As patients in the public sector normally has no medical aid, the fact that only one patient from this group, previously a private sector patient, mentioned medical aid benefits can be expected. The following comment was made: *"…had to move to a government-funded treatment facility because my medical aid had been exhausted…"*

Patients from the private sector group reported the following: *"…it would probably have been a bigger problem if I didn't have a medical aid, because then I would have had to go to a government hospital…"*; *"…if I had not had medical aid…I might have gotten inadequate treatment or substandard medication and would probably have died…but now I am living a relatively normal life…"*; *"…the communication and support from my medical aid is unbelievable…such a relief…less stress, leaving me to focus on getting better…"*; *"…continually worried if medical aid is still going to cover next session…"* and *"…I'll only accept treatment covered by my medical aid…don't want to bankrupt my family and end-up dying anyway…"*

Something that both groups, however, agreed upon was the fact that ideally treatment should be equally accessible and more affordable.

### Theme 10: Healthcare professionals

Differing perspectives and experiences regarding the medical staff were noted not only between the two groups but also within each group respectively. Patients in the private sector reported experiencing the nursing staff in a purely positive light. According to them the nursing staff was caring, competent and had good communication and interpersonal skills. Comments made regarding the nursing staff included: *"…you walk in and they make you feel like the only patient, like you really matter…"*; *"…have confidence and trust in their abilities…"*; *"…make you feel comfortable and welcome to ask any questions or for anything needed…"*; *"…open…communicate effortlessly…"*; *"…treat me with respect and dignity…"*; *"…has a passion for working with people…"* and *"…very compassionate…have a sense of humour which helps a lot…"*

Patients in the public sector group reported differing experiences. While the majority describe having a similar experience as that described by the private sector group, a minority described the nursing staff in the public sector as being incompetent and unprofessional. Comments depicting this differing experiences included: *"…very busy but they cope very well…"*; *"…struggle to organise their day…causes unnecessary frustrations…"*; *"…most are excellent and treat patients with empathy…"*; *"…disappointed in them, they're rude and they treat patients badly…one actually told me that they were doing us a favour…they have no respect…"*; *"…caring and compassionate…provide a sense of hope…"* and *"…answer their cellphones during consultations…very unprofessional…"*

Within the private sector treatment group the medical officers and oncologists were seen in a mainly positive light. Patients described them as being competent and reported having trust in their abilities. They were also considered as having good interpersonal skills with the only drawback being lack of accessibility and the limited time they got to spend with their oncologists. Comments made in this regard included the following: *"…absolute confidence and trust in their abilities…"*; *"…very professional and meticulous…"*; *"…very caring and attentive…"*; *"…patient and understanding…"*; *"…feels like they are focused only on me when I'm with them…"*; *"…wonderful and sincere and so sad that they could do no more to help me…"* ; *"…unable to get hold of them…"*; *"…limited time…would like the opportunity to ask more questions…"* and *"…had to wait for more than a month before I could see an oncologist…makes you anxious…"*

Once again the patients in the public sector group reported differing experiences. When it came to the medical officers and oncologists providing their treatment some described having a positive treatment experience, while others reported having no trust in their ability and felt they were unapproachable. A few of the comments made included: *"…good at their job…"*; *"…I was thoroughly examined and treated very well…"*; *"…trust them to do the right thing…"*; *"…treated me with respect and dignity…"*; *"…explained the situation well…"*; *"…felt rushed…"*; *"…not the kind of person you can talk to…kind of* *rude…don't really feel comfortable enough to ask any questions…"*; *"…sometimes I feel like just a number…"*; *"…don't give you clear information…everything is vague…"*; *"…take no personal interest…feels like they tell all their patients the exact same thing…have my doubts regarding their abilities…"*; *"…cold and impersonal…"* and *"…makes me a bit edgy because he is so reserved, which makes him seem strict…almost like he won't answer my questions…"*

While some healthcare professionals were able to meet patients' expectations the conduct of others were considered sadly lacking. The following were reported by both groups as being the ideal: honesty, friendliness, empathy and understanding, patience, respect, to be treated 'normally', equality, sense of humour, and acknowledgement of individuality and personal experiences. One of the patients in the public sector group explained this last sentiment as: *"…I feel that the doctors have medical knowledge regarding what you have to go through but they haven't experienced it for themselves. Academically they understand but they have no personal understanding. Therefore, when you share your personal experiences I want them to place more value on your experience…"*

Very little mention was made of other allied healthcare professionals providing treatment. Any statements made were brief, yet of a positive nature. The following professions were mentioned: social workers, psychologists, radiation therapists, spiritual healers and administrative staff.

### Theme 11: Research

Both groups were of the opinion that more research should be conducted, especially in the light of the high incidence rate of cancer in South Africa. This was described by one of the patients in the following way: *"…almost every second person has cancer these days…therefore I would like for them to work in depth at getting to a cure…"*

Patients in the private sector group were of the opinion that the research being conducted locally compare well internationally. They do, however, feel that more international corroboration is important and that a key focus area would be how to apply or make accessible that which is discovered. One of the patients in this group made the following comment: *"…I believe that at 'top levels' we compare well with other countries…we just need to work on accessibility…"*

Patients in the public sector group felt that cancer research should focus on refining current treatments by incorporating natural remedies, finding a way to minimise side-effects, and finding a cure. Comments made in this regard included: *"…a lot of people don't only* *use chemo- or radiation therapy…they also use herbs…I feel that these remedies should be tested to see if it can't be used in conjunction with the prescribed treatment… sometimes these remedies actually help…"* and *"…I wish there were more success stories… I feel they have to study more and find a cure..."*

### Theme 12: Changes needed in the treatment process

While both groups expressed being appreciative of the treatment they are currently receiving they also had numerous suggestions for how treatment could be improved within a South African context. Although the majority of the improvements suggested, were similar for both groups there were, however, a few that were distinctive to either the private or public healthcare sector.

Suggestions made by both groups included the addressing of cultural issues; transport and/or travelling distances; increased treatment availability and treatment sites; and decreasing side-effects. Although patients from both groups reported struggling with various issues related to culture, the effects and levels of frustration thereof was much more evident within the public sector. The only concern private sector patients seem to have in this regard is the volume at which certain cultures communicate. The following comment was made: *"…staff should be more culturally sensitive…African people talking loudly and shouting frustrates me…I'm unable to handle it…"* This experience was shared by patients receiving government-funded healthcare, with one patient in the public sector group commenting: *"…the loudness of African staff really grates on my nerves…"* For the majority of the public sector group the biggest culture-related concern, however, appeared to be language-related. Interestingly enough, this was experienced not only among Xhosa-speaking patients but amongst Afrikaans- and English-speaking patients as well. The following was reported: *"…I'm not one of those highly educated people that know a lot of English…sometimes I feel like I should just take my bag and leave…because I don't really understand what is going on…"*; *"…have a lot of questions, but I keep on seeing an African doctor…he doesn't understand me…"*; *"…language is difficult…sometimes they need to call a Xhosa sister to make the doctor understand…"* and *"…consulted a Black doctor who was unable to speak Afrikaans…this was an awful experience…because how can I explain how I'm feeling if he doesn't understand me…I'm able to speak English, but I can't always express myself as well…"* A possible solution to the above-mentioned problem, as suggested by the patients, is to have patients consult with doctors who are of the same culture as them. The following statements were made in this regard: *"I feel comfortable and safe with people who can speak* *my language…"*; *"…I would like to consult with someone who is the same culture as me for language purposes…"*; *"feel that they should put Africans with Africans and Coloureds with Coloureds…this way they will be able to understand each other well…"* and *"…to put the same cultures together, doctor and patient…so that there can be a better understanding for each other…"*

Another concern that both groups felt needed addressing was the transport and/or travelling distances involved in seeking treatment. Most of the patients have to travel long distances in order to get treatment as the majority of the smaller towns in the Eastern Cape do not provide any local treatment sites. The main concern expressed within the private sector group was the financial implications associated with travelling and the frustrations of making use of public transport services. Comments included: *"…travelling…on a regular basis has proven to be very expensive…"* and *"…getting to treatment is a challenge as I have to make use of public transport…which is a nuisance…"* This appears to be an even bigger problem for patients from the public sector as apart from a strenuous journey due to long travelling distances, they report having the added concern of having no funds for public transport. One patient reported the following: *"…transport is very bad…I don't always know how I'm going to get home…I have to get to treatment by myself…take a taxi by myself…after treatment I feel very bad…then I just walk slowly to the taxi rank…praying the whole way that I won't faint…"* Government-funded hospitals generally provide hospital transport to its patients but as can be seen by the following statements, this does not appear to be a solution either as it is often unreliable and even dangerous: *"…had to borrow money to get back home…because the hospital transport left without me…it was very distressing…I had no money and no airtime…it was a horrible experience…"* and *"…not really a transport vehicle…patients have to sit on the beds in the ambulance…sometimes its overloaded…"* Assistance to and from the hospital was suggested as a possible solution for addressing the previously mentioned difficulties. Theoretically, government hospitals already provide transport services but it is the implementation thereof that appears to be the main problem. One patient made the following suggestion: *"…government is providing free hospital transport and free treatment services…but it needs to be monitored so that it can run as it is supposed to…"*

Both groups also suggested expanding treatment sites to rural areas and smaller towns as this will cut back on travelling times and expenses. Public sector patients felt that this would decrease patient numbers at any one site, which could possibly lead to more efficient services and shorter waiting times. One way to accomplish this would be to update and improve treatments provided at clinic level. A patient in the public sector group made the following comment: *"…clinics never have the stuff that is needed for treatment…clinics need to be updated…then we'll be able to get treatment there and it wouldn't be necessary to take three taxi's to get to the hospital for treatment…"*

As previously mentioned in the themes 'experience of treatment' and 'research', the side-effects associated with treatment were one of the main difficulties experienced by cancer patients and were, therefore, one of the main focus areas for changes needed in the treatment process. Pain, fatigue, nausea and hair loss were the side-effects identified as the ones they would most like to be rid of. Most of the comments made were, however, done in an almost wistful way as they have come to accept them as part of the process. One of the patients in the private sector group said: *"…obviously one would like to get rid of all side-effects…but that's not a realistic wish because it comes with the cancer…"* Other comments made, included: *"…wish it was less physically and emotionally painful…"*; *"…take the nausea away…"*; *"…take away the tiredness…"* and *"…invent something that can prevent hair loss…this will provide more privacy and prevent unsympathetic remarks…privacy for your condition…it won't be written all over your face that you're a cancer patient…"*

Changes specifically indicated by the private sector group included finding a cure, aesthetic improvements to treatment sites, and gender equality with regard to the target group for cancer campaigns and promotions. While the majority of the patients in the private sector treatment group reported being satisfied with the treatment they are receiving, a few expressed the need for more assurance regarding a cure. Some of the comments made included: *"…they are doing the best available…"*; *"…what we're getting is the best…"*; *"…satisfied with everything…"*; *"…find a cure for all cancers…"*; *"…guarantee to cure cancer…"* and *"…that if one alternative doesn't work…that there will always be something else they can try…"* They also seem to appreciate the aesthetic qualities associated with private treatment facilities, as a nicely decorated environment is less depressing, regardless of one's reason for visiting. One patient made the following comment: *"…keep going the way we are…an environment that is less clinical…give softer or easier on the ear names…like change from 'chemo room' to 'chemo lounge'…"* Something else that they feel need to change is the fact that the majority of cancer campaigns and product promotions mainly target women. One patient commented: *"…everything is pink…I feel that male patients get neglected when it comes to cancer campaigns and promotions and things…the women are spoiled with make-up sessions…people come in and do their nails…everything is aimed at women, there is nothing like that for the men…"*

Changes specifically indicated by the public sector group included increased productivity and efficiency, staff competence, and doctor continuity. As previously discussed during the themes 'experience of treatment' and 'healthcare professionals', many of the frustrations experienced within the public sector appear to be systemic-based, lack of resources, staff shortages and inflated patient numbers to name but a few. The patients do, however, feel that some of their frustrations could be alleviated with minor adjustments despite the above-mentioned problems. Some of the suggestions they made included: *"the process needs to be streamlined…"*; *"...some sort of appointment system in both the chemo and bone scan department as patients all arrive at seven am in the morning and it becomes a very long day…an appointment system would perhaps alleviate this problem…"* and *"…increase productivity...they should stop the nursing staff's dawdling…instead of helping people they're forever walking up and down…"* Another area in which they feel changes should be made is that of staff competence. Comments made in this regard included: *"...you have to put the right people in the right positions…it doesn't help to put a doctor at a specific site and then he doesn't know what is going on there…"*; *"...I feel that some staff members could show a bit more empathy…"*; *"...staff should be trained to understand the emotional pain cancer patients go through…"; "...staff members that are rude to patients shouldn't be working in an oncology department as this is anxiety provoking…"*; *"…earlier diagnosis…it shouldn't take three months to get to a diagnosis…"* and *"...should be given more options…I only learned about other things they maybe could have done afterwards…"* Another way in which they thought some of the above-mentioned problems could be addressed is by developing an appointment system that allows for doctor continuity. In other words, each patient would be allocated to a specific doctor. The patient would then consult with the same doctor on each occasion allowing the doctor to become familiar with the said patient and his or her treatment requirements. The following comments were made in this regard: *"...I would like to see the same doctor every time…so that he gets to know your case and you can build a relationship…now they have to look in the file all the time…it's impersonal…"*; *"…to see the same doctor every time…if you are familiar with a doctor there are things that you can ask or tell them...sometimes you feel uncomfortable talking to a different doctor every time…"*

**Quantitative NEQ results**

As indicated by the themes identified above, some obvious differences could be identified between the treatment experiences of the private and public sector healthcare patients. In an attempt to see whether this would also be true if tested quantitatively, a statistical significance test (t-test) was applied to the data gathered by means of the NEQ in order to determine whether or not the difference between the means for the government-funded healthcare group and the private healthcare group was significant. A p-value smaller than 0.05 is considered as sufficient evidence that the result is statistically significant (Ellis & Steyn, 2003).

[place table 2 here]

Based on this assumption, the results (table 2) thus indicate a significant statistical difference between the needs of patients receiving government-funded treatment and those receiving private healthcare. However, statistical significance does not necessarily imply that the result is important in practice (Ellis & Steyn, 2003), therefore, effect sizes were determined in order to establish whether there is a large-enough difference between the means to have an effect in practice. According to Cohen's (1988), guidelines the following interpretations of effect sizes can be made: $d = 0.2$ indicates a small effect, $d = 0.5$ a medium effect and $d = 0.8$ a large effect. The results, as shown in table 2, indicate the presence of a practical significance between the two groups with the subscales assistance/care and psycho-emotional support showing a medium effect, while the informative-, relational- and material-needs subscales indicated the presence of a large effect. Therefore, the results obtained can be considered statistically and practically significant despite the small sample used. Based on these results one could conclude that the patients receiving government-funded healthcare report having more unsatisfied needs than those from the private sector, which is in concurrence with the themes as identified by making use of qualitative content analysis.

## Discussion

The impact of cancer traverses cultural background, socioeconomic status, age, gender, and geographical location with the impact of psychosocial distress affecting all areas of patients' lives (Kenny, Endacott, Botti, & Watts, 2007). This was evident in the amount of similarities identified in the present study as patients from both the private and public sector reported having various similar experiences with regard to cancer treatment. How cancer affects patients' lives and experiences are, however, often directly influenced by factors such as their cultural background, socioeconomic status and geographical location (Cooper & Mullin, 2001). These effects can clearly be seen by the differential treatment experiences reported by the private and public sector groups. It is, therefore, important for healthcare professionals to acknowledge the impact of treatment on patients' lives rather than exclusively focusing on the physical outcomes (Selman et al. 2011).

Both groups reported their overall experience of treatment as being positive, as actively receiving treatment made them feel proactive and provided them with a sense of hope. Research has shown that most patients are willing to accept treatment for small to modest potential benefit (Lindley, Vasa, Sawyer, & Winer, 1998). By doing something active, patients and physicians alike, are provided with a semblance of control over the disease process (De Haes & Koedoot, 2003). Perceived control during experiences of uncertainty allows for the maintenance of hope (Truant & Bottorff, 1999). According to Twycross (1997), hope, or even a realistic level of optimism with attainable goals, is considered an important aspect of cancer treatment. A minority of patients in the public sector treatment group reported the 'costs' associated with treatment as outweighing the benefits. This is believed to be associated with the systemic difficulties associated with public healthcare. Having to rely on the public healthcare sector's overburdened and underfunded facilities (Krombein & De Villiers, 2006), often result in patients having to endure long waiting times, causing them to become despondent and even desperate (Bateman, 2011). Although patients in the private healthcare group did not report having to endure long waiting times, they did experience the time allocated to receiving treatment as being bothersome, as it often affected various aspects of their lives. According to Gupta, Grutsch, and Lis (2008) the effects of cancer and its treatment can lead to impairment in multiple areas of a person's functioning ranging from the ability to perform tasks of daily living to deriving comfort from one's health. The side-effects experienced and the lifestyle changes this necessitates will be discussed at a later stage.

Despite the fact that the patients receiving private healthcare expressed overall satisfaction with the treatment received, the majority of them expressed concern for patients who only have access to government-funded healthcare. Their empathy could possibly be attributed to personal growth, leading to a deeper appreciation for life, or it could be seen as a form of downward social comparison. Social comparison is a defensive tendency used as a means of self-evaluation. Comparison with an individual or group who are believed to be worse off allows people to dissociate themselves from perceived similarities. This downward contrast may lead to positive feelings, improving their perception about themselves or their circumstances (Brakel, Dijkstra, Buunk, & Siero, 2012).

Unfortunately patients' difficulty in dealing with the healthcare system often starts even prior to being diagnosed with cancer. Patients are often mismanaged by healthcare professionals with the average number of months from first consulting with a healthcare professional until diagnosis ranging from 11.8 to 28.4 months (Van Schalkwyk et al. 2008). Dye et al. (2010), describe the process of diagnosing cancer as often being confusing and inefficient. Patients from both groups reported experiencing a delay in diagnosis as it often takes many inappropriate diagnoses and inadequate treatments before a diagnosis of cancer is researched. Both groups then also expressed being shocked initially by a cancer diagnosis but also expressed feeling a sense of relief thereafter as knowing what is wrong and needs treating provides them with a sense of control (De Haes & Koedoot, 2003). Patients from both groups expressed a need for earlier diagnosis as this could possibly lead to treatment at earlier stages of disease severity and, therefore, a better chance at being cured. Patients felt that General Practitioners should receive additional training with regards to identifying and diagnosing cancer. This sentiment is shared by Van Schalkwyk et al. (2008), who reported that it was a lack of knowledge and awareness which often resulted in a low suspicion of cancer and misdiagnosis. While patients from both groups expressed similar experiences during the diagnosis phase they expressed differing needs regarding the commencement of treatment. Patients in the private sector expressed the need for more time to come to terms with their diagnosis while those in the public sector appreciate the quick commencement of treatment. A reason for this could be that those receiving public healthcare know that life-threatening waiting times and delays are often a reality (Bateman, 2011) and entering the treatment process as quickly as possible thus becomes a priority.

Cancer care is however neither easy nor straightforward (Wilson, 2009) and both groups stated fear of the unknown, myths about certain treatments, and testimonials from fellow cancer patients regarding the adverse effects of treatment as being anxiety provoking. According to Bar-Tal, Barnoy, and Zisser (2005), in addition to the life-threatening aspects of cancer, uncertainty is considered one of the major stressors for patients with perceived stigma, ignorance, misconceptions and insufficient knowledge further attributing to their ‘expecting the worst’ mentality. Both groups did however feel that they were able to cope quite well once they had started treatment as they were then able to assess their reactions to treatment for themselves and, therefore, stress the importance of acknowledging patient individuality when it came to cancer treatment and ones reaction thereto. This is supported by Arora, Street, Epstein, and Butow (2009), who recognise the importance of personalised medicine which comprises of a healthcare delivery system that is responsive to the needs of patients and encourages them to take an active role during treatment.

Before treatment can be started however decisions regarding an appropriate treatment route need to be made. Informed consent then also needs to be obtained. For any of this to take place patients require adequate information and communication opportunities with healthcare professionals. Both groups reported having limited understanding of cancer prior to diagnosis. Those in the private sector group reported being well informed with the minority of the public sector patients sharing this experience. The majority of the public sector patients however reported experiencing uncertainty, limited comprehension and poor communication. The medical terminology used was considered problematic to a minority of the private sector patients, as well as to the majority of the public sector patients. According to Baile and Aaron (2005), the communication between cancer patients and healthcare professionals has a powerful impact on how patients conceptualise, make decisions about, and cope with their illness. Patients who have received inadequate information prior to receiving treatment may experience more anxiety, pain and side-effects (Maboko & Mavundla, 2006). On the other hand, too much information about the adverse effects that can be expected could lead to patients reacting to even the slightest indication of what they anticipated (Masalla, De Waal, & Friedrich-Nel, 2010). The importance of appropriate information can, therefore, not be overstated. Unfortunately healthcare professionals seldom have the necessary skills to determine and respond to patients' individual information needs. They are often unable to explore patients' perceptions and reactions to the treatment process and are thus unable to respond accordingly (Maguire & Pitceathly, 2003). Merely providing the right amount of information is, however, not enough as good care, from the patients' perspective, involves using understandable language when providing information about their disease and the treatment process thereof (Kvåle & Bondevik, 2008). The differences experienced between the private and public sector patients once again comes down to the fact that those in the private sector have better access to information due to the availability of various resources, while those in the public sector is served by overburdened staff with limited resources at their disposal (Bateman, 2011).

Davison, Kirk, Degner, and Hassard (1999), are of the opinion that the provision of information and communication is closely associated with the decision-making process, and believe that this will affect patients' willingness and ability to participate in treatment related decisions. Patients in the private healthcare group reported feeling included in treatment decisions with a minority of those in the public sector sharing this experience. The majority of the public sector patients reported feeling excluded when it came to making decisions about their treatment. Although both groups expressed being comfortable with leaving the final decision regarding treatment to the healthcare professionals, the extent to which they wished to be consulted differed significantly from patient to patient regardless of where treatment was being received. Although the majority of cancer patients prefer being informed about different options during the decision-making process, interest in actually making treatment decisions vary considerably from patient to patient (Say, Murtagh, & Thomson, 2006). According to Pålsson and Norberg (1995), the relationship between patient and physician plays an important part in the decision-making process if a collaborative approach tailored to the needs and wishes of the patient is to be achieved (Sinfield, Baker, Agarwal, & Tarrant, 2008). For this to be accomplished, the physician needs to develop rapport with the patient by establishing an open line of communication (Pillay, 2001). Patients seem to appreciate involvement and direction from healthcare professionals, viewing their expertise as being of value rather than as an impediment to patient decision-making (Sinding et al. 2010). Facilitating patient involvement in treatment decisions would involve providing them with more time, support and knowledge (Pålsson & Norberg, 1995), all of which the public healthcare system with its large patient numbers and lack of resources struggle to provide (Bateman, 2011). Patients in the public sector may also perceive their treatment choice as not really being much of a choice at all, as treatment is often determined by its place in the government-funded formulary (Sinding et al. 2010).

An almost inevitable consequence of starting treatment is the onset of a wide range of distressing side-effects (Porter et al. 2002). The side-effects associated with cancer treatment were identified by both the private and public sector patients as one of the main difficulties encountered during treatment. The most common side-effects identified included: pain, fatigue, nausea, hair loss, loss of appetite, mouth and throat sores, and dizziness. As many as 80% of patients with late stage cancer report experiencing significant pain, which make them more likely to experience other cancer-related symptoms as well (Porter et al. 2002). According to Nuhu, Odejide, Adebayo, and Yusuf (2009), there is a significant association between pain and fatigue which influences patients' ability to function in everyday life.

The effects of cancer and the treatment thereof can result in difficulty and role-transitions in multiple areas of a person's functioning (Beatty, Oxlad, Koczwara, & Wade, 2008). Patients from both the private and public healthcare groups reported having to make various lifestyle changes in order to accommodate treatment regimes and side-effects. As previously mentioned both groups reported having to make adjustments to their schedules as a result of the amount of time needed for treatment. The private sector group reported having to make provision for the time it actually takes to receive treatment, while the public sector group reported having to take into consideration not only the time allocated to actually receiving treatment but long waiting times as well. Some of these changes are also believed to be the result of financial necessity and others to be brought about by the development of new perspectives. The costs associated with cancer treatment are often more than expected (Mathews, West, & Buehler, 2009). Patients in the public sector group reported having difficulty affording basic necessities in addition to medical care. Regardless of having a good medical aid the added financial burden due to out-of-pocket costs often requires private sector patients to make various lifestyle changes as well (Mathews et al. 2009). Similar results were found by Serin et al. (2004), who reported experiencing problems with housework, child care, professional life, finances, and relations with family and friends as areas in which patients encountered difficulty during treatment.

Various coping strategies, ranging from the metacognitive to the practical, were employed by both groups in an effort to cope with their cancer diagnoses and the treatment thereof. Patients in the private sector primarily made use of emotion-focused coping, using metacognitive capabilities to alter negative effects through restructuring cognitions, while those in the government-funded treatment group employed problem-focused coping strategies. According to Carver, Scheier, and Weintraub (1989), emotion-focused coping is associated with positive reinterpretation and growth, while problem-focused coping involves active coping, planning and seeking support for instrumental reasons. A possible explanation for this could be that the majority of the patients in the public sector group would be considered as functioning on the lower levels of Maslow’s hierarchy of needs (Maslow, 1954), as their physiological and safety needs remain mainly unsatisfied due to poor socioeconomic circumstances, while the private sector is often represented by patients enjoying a higher socioeconomic status. Religion was also seen by both groups as providing an invaluable source of support as having faith increased their coping abilities. Religion is often used by cancer patients as a coping strategy (Ogden, 2004), as it provides them with a coherent belief-system within which the meaning of life and hope for the future can be found (Seligman, 2002).

Another source of support that is often considered as being invaluable is familial support. Cancer patients are often concerned about how healthcare costs will affect the financial and social security of their families over time (Pillay, 2001). While patients in both groups expressed their appreciation for the support provided by family members, public sector patients also expressed concern and guilt over the impact their illness was having on their family. Beatty et al. (2008), support this by stating that patients commonly report experiencing concern for the stress and adjustment difficulties often experienced by family members. Thomas, Morris, and Harman (2002), states that if there is practical and emotional involvement by family members their own lives can be affected in profound ways, especially when considering the additional care work demands cancer patients often require. The fact that the public sector patients expressed more concern with regards to the impact their illness was having on their families can possibly be explained by their socioeconomic circumstances. Carers' own morbidity status, as well as their material and social circumstances play an important role in their capacity to take on greater quantities of care work (Thomas et al. 2002).

Another result of poor socioeconomic circumstances is lack of adequate health insurance, as not having a medical aid may prevent patients from seeking treatment or result in them not taking the necessary medications or failing to attend follow-up appointments (Institute of Medicine, 2007). As previously mentioned, the costs associated with cancer treatment is often more than expected (Mathews et al. 2009), and concern about medical aid depletion or recommended treatments not being covered by one's medical aid scheme is thus to be expected, especially, if this might result in having to make use of overburdened, under-resourced government-funded facilities (Bateman, 2011). Both groups felt that treatment should be equally accessible and more affordable. This is supported by Ward et al. (2004), who state that when it comes to cancer survival socioeconomic factors, such as poverty, poor education and lack of health insurance, plays a far more important role than biological differences. It is for this reason that eliminating health disparities should be prioritised.

Healthcare professionals can be considered as being the backbone of any healthcare system. The way in which they are perceived, often shape patients' perceptions of treatment (Venter et al. 2008). Patients in the private sector group reported positive experiences with regard to the healthcare professionals providing their treatment. Nurses, medical officers and oncologists were seen as being competent and caring with the only problem area identified, being the lack of time and accessibility to oncologists due to the large number of patients they have to serve. While the majority of patients in the public sector group reported being satisfied with the treatment being provided, a minority of them described the healthcare professionals providing their treatment as being incompetent and unprofessional, as well as doubting their abilities. According to Royak-Schaler et al. (2006), access to healthcare professionals is one of the main factors influencing perceptions of care as being positive or negative. Oncology is often described as being a stressful and difficult working environment (Van Rooyen, Le Roux, & Kotzé, 2006), where finding a balance between task completion and ‘care’ remains an endless challenge (Kenny et al. 2007). The difficulties experienced by the public sector group could possibly be attributed to too few doctors seeing too many patients, thus compromising patient care. In these instances, patients could experience healthcare professionals as being too busy to provided quality care, which may result in them questioning the competence of those providing their treatment (Royak-Schaler et al. 2006). According to Kelly, Ghazi, and Caldwell (2002), it is very important for healthcare professionals to support patients’ ideas and feelings, as this is believed to promote the concept of hope. On the other hand, should patients feel that their expectations are not being met, a sense of hopelessness could arise. Both groups indicated the importance of acknowledging patient experiences, reporting the need for healthcare professionals to place more importance on patient perception. This is supported by Carlsson, Segesten, Nilbert, and Nilsson (2007), who acknowledge the importance of balancing experiential and professional knowledge when treating cancer patients.

Due to the high incidence of cancer, both groups reported that more cancer research should be conducted. Based on mass media influences and internet searches, those in the private sector believe South African cancer care to be on par with international standards and that it is mainly the access to quality care that remains a problem. This perception is supported by one of the patients mentioned in Bateman’s (2011) article, who reported that although South Africa has some of the best cancer doctors in the world, one’s ability to access their expertise is dependent on one’s financial status. The fact that both groups felt so strongly about continuous research could possibly be associated with the concept of hope. While research is being conducted, finding a cure remains a possibility. According to Jarrett and Payne (2000), hopefulness regarding the future is generally viewed as being an important aspect of cancer care.

The complexity of cancer treatment along with the need for individualised treatment regimes based on each patient’s needs is no easy feat. Based on their personal experience with cancer treatment, both groups made numerous suggestions on how cancer treatment can be improved within the South African context. Although the majority of the suggestions made were similar for both groups, there was, however, a few suggestions that were more group-specific and will, therefore, be discussed as such.

Changes indicated by both groups included the addressing of: cultural issues; transport and/or travelling distances; increased treatment availability and treatment sites; and decreasing side-effects. Culture plays an important role in how cancer and the treatment thereof are perceived (Van Schalkwyk et al. 2008). The multi-ethnic nature of South Africa and the fact that there is no single dominant language give rise to numerous challenges within the healthcare system (Mullin et al. 2000). The biggest culturally based challenge appeared to be language-related, with patients indicating a preference for being treated by healthcare professionals belonging to the same culture as them as a way to bridge the communication gap. This is supported by Cooper and Mullin (2001), who reported that various studies have indicated that even without cultural differences the communication between cancer patients and the healthcare professionals providing their treatment is often difficult. These difficulties become significantly greater in cross-cultural contexts, which may even lead to compromised treatment. The implementation of such a strategy might prove challenging in post-apartheid South Africa, as it might remind people of past segregation laws.

Both groups reported transport and travelling distances as impeding cancer care. This is supported by various studies stating travelling and travel-related costs as being obstacles in cancer screening and treatment (Krombein & De Villiers, 2006; Van Schalkwyk et al. 2008; Mathews et al. 2009). Patients' suggestions to alleviate this included the provision of effective hospital transportation, improving community clinics and establishing more treatment sites so that there would be less need to travel to hospital for treatments. According to Anderson, Goldberg, Algar, Felix, and Ramesar (2007), the majority of cancer treatment services are only available in the major centres in South Africa. Patients thus need to visit various facilities, which are often unevenly distributed in different locations, for different services (Dey et al. 2010). The travelling and accommodation required to access these services add to the economic burden patients are already experiencing (Anderson et al. 2007). Clinics are often plagued by inadequate resources, poor referral systems, insufficient recordkeeping and inadequate feedback services (Sibiya & Grainger, 2007). If the availability of treatment is to be improved, the development of clinics and additional treatment sites are crucial. For this to take place South Africa would have to find adequate financial resources, develop the infrastructure, train the needed healthcare professionals, and find ways to monitor and maintain the quality of treatment services.

Efforts to decrease side-effects were also suggested by both groups as an area for possible improvement. As previously discussed, cancer patients are often plagued by a wide range of distressing side-effects, which affect their ability to function in everyday life. The fact that patients in both groups expressed the need for the elimination of side-effects in an almost wistful way, as many have come to accept them as simply being part of the process, is supported by Selman et al. (2011), who suggest that physical symptoms and discomfort are less important to patients' quality of life than the other domains thereof. According to

Padilla, Ferrell, Grant, and Rhiner (1990), this is because cancer patients generally readjust their expectations to be in line with their health and functional status.

Changes indicated by the private sector group included finding a cure, aesthetic improvements to treatment sites, and gender equality with regard to cancer campaigns and promotions. Although the majority of the patients in the private sector group were predominantly satisfied with the treatment they received, the need for assurance regarding a cure was indicated. As previously indicated, while the belief that persistent research for finding a cure is being conducted, the hope for finding a cure and thus survival is kept alive. While some might find their concern about aesthetic improvements as being odd, especially when patients in the public sector do not even have the resources necessary for survival, research has shown strong scientific evidence that environmental factors can directly promote or hinder health and wellbeing (Salonen et al. 2013). According to Edvardsson, Sandman, and Rasmussen (2005), sensing an atmosphere of ease conceptualises an environment as being conducive to supportive care. The following five factors were identified as underlying an atmosphere of ease: safety, feeling welcome, being able to identify with and feeling comfortable in the environment, social support, and experiencing staff as willing and eager to serve (Edvardsson et al. 2005).

The reasons why the focus of cancer campaigns are likely to be experienced as being disproportionate in terms of gender can possibly be found by looking at their history and the methods which are typically employed. Two of the most well-known campaigns in South Africa include the “Look Good Feel Better” public service programme and “Movember”. While the “Look Good Feel Better” programme was launched in 1989 in the United States (Look Good Feel Better, 2013), “Movember” only came about in 2003 in Australia (Movember, 2013). “Look Good Feel Better” is a public service programme that helps women manage the appearance-related side-effects of treatment by making use of group workshops led by cosmetology professionals using products donated by the cosmetic industry (Look Good Feel Better, 2013). “Movember” comes about each year during the month of November when men around the world are seen sprouting moustaches in an attempt to raise funds and awareness for men’s health, specifically prostate and testicular cancer (Movember, 2013). The hands-on approach of the ‘Look Good Feel Better’ initiative and the fact that pink ribbon ‘cause marketing’ is associated with various leading brands (Baralt, 2006), and can be seen all year round make the efforts being put into breast cancer awareness very visible to the public. Although it is almost impossible to determine if the involvement of certain corporations in the pink-ribbon campaign is authentic and if the funds raised are being well spent (Baralt, 2006), the public perception that ‘something is being done’ remains indisputable.

Changes indicated by the public sector group included increased productivity and efficiency, staff competence, and doctor continuity. As previously discussed, the lack of resources and high patient turnover, which is typically found in the public sector, would make the implementation of the patient-suggested strategies, regarding increasing productivity, difficult to implement. The public healthcare sector is mainly staffed with intern and community service doctors. According to a study conducted by De Villiers and De Villiers (2006), newly qualified doctors often lack self-confidence and the self-perceived competency to function unsupervised in district hospitals. Intern and community service doctors also seldom remain employed at the hospital responsible for this period of their training. This coupled with the large number of patients presenting to government-funded hospitals for treatment makes doctor continuity difficult to attain. It should, however, be noted that continuity of care is considered an important factor in patient satisfaction with care, as well as the level of trust placed in the healthcare professional. Being continuously treated by the same healthcare professional often results in them gaining a better ‘non-biomedical’ understanding of the patient involved, resulting in a relationship based on mutual understanding and trust (Michiels et al. 2007). The employment and retention of more permanent, experienced healthcare professionals are thus crucial, especially if one considers the fact that positive perceptions regarding the competence and availability of healthcare professionals are associated with the report of more positive illness experiences (Royak-Schaler et al. 2006; Venter et al. 2008).

## Conclusion and Recommendations

The importance of structural and environmental issues associated with the quality of healthcare has once again been confirmed as the majority of the differences regarding treatment experiences between the two groups can be traced back to systemic problems in the public sector due to lack of technical and human resources. According to the Universal Declaration of Human Rights (United Nations, 2013),

> “Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.” (Article 25, No. 1)

This is, however, not always attainable in a South African context due to a lack of resources where access to quality healthcare seems to be determined by socioeconomic status. Government policy addressing the above-mentioned discrepancies needs to be developed and the ones in place need to be better managed and enforced.

The following recommendations with regard to attaining quality cancer treatment can be made:

- Increase treatment availability by increasing the number of treatment sites, as well as by updating existing treatment sites.
- The implementation of hospital policies regarding the productivity and efficiency of quality care and patient transport needs to be continuously monitored and enforced.
- Treatment should take place in a calming and relaxed atmosphere.
- Competency of staff should be ensured and continuous professional development in areas related to cancer treatment should be encouraged.
- Continuous research focusing on refining treatment and finding a cure should be conducted.
- Efforts to ensure earlier diagnosis should be undertaken. This could be accomplished by improving cancer awareness, implementing more effective screening programmes and training general practitioners to be more competent in diagnosing cancer.
- Healthcare professionals should receive communication skills training focusing on tailoring information to patients' individual needs, as well as how to convey specialised medical information in an understandable way.
- Building rapport and maintaining a continuous supportive professional relationship with patients should be encouraged.
- Healthcare professionals should provide guidance, yet encourage patient inclusion and participation in making treatment decisions.
- Patient experiences should be acknowledged and taken into consideration throughout the treatment process.
- Healthcare professionals should be culturally sensitive and provide treatment accordingly.
- The importance of providing treatment information and care in the patient's first-language should be acknowledged.
- Awareness campaigns focusing on male cancers should be increased as to be on par with awareness campaigns focusing on female cancers.

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# Addendum 1

Cancer treatment questionnaire

1) What has your experience with cancer treatment been like?
2) What were/are the benefits you experienced regarding treatment?
3) What were/are the challenges/obstacles you experienced regarding treatment?
4) What are your views on the information provided and communication opportunities during the treatment process?
5) Which professions have you consulted/were involved in your treatment?
6) a) How do you feel about the professionals providing your treatment?

   b) What do you want most from the professionals providing your treatment?
7) If you had the power to change anything regarding the cancer treatment process what would it be and why?
8) What is the one thing you wish the professionals providing your treatment understood?
9) In your opinion, how can we improve cancer treatment in South Africa?
10) We are interested in any other comments you might have concerning your treatment experience. Please write in the space below anything you would like us to take note of.

## Addendum 2

Needs evaluation questionnaire

1. I need more information about my diagnosis (Yes/No)
2. I need more information about my future condition (Yes/No)
3. I need more information about the examinations I am undergoing (Yes/No)
4. I need more explanations of treatments (Yes/No)
5. I need to be more involved in therapeutic choices (Yes/No)
6. I need clinicians and nurses to give me more comprehensible information (Yes/No)
7. I need clinicians to be more sincere with me (Yes/No)
8. I need to have a better dialogue with clinicians (Yes/No)
9. I need my symptoms (pain, nausea, insomnia, etc.) to be better controlled (Yes/No)
10. I need more help with eating, dressing, and going to the bathroom (Yes/No)
11. I need better respect for my privacy/intimacy (Yes/No)
12. I need better attention from nurses (Yes/No)
13. I need to be more reassured by the clinicians (Yes/No)
14. I need better services from the hospital (bathrooms, meals, cleaning) (Yes/No)
15. I need to have more economic-insurance information (medical aids, invalidity, etc.) (Yes/No)
16. In relation to my illness I need economic help (Yes/No)
17. I need to talk to a psychologist (Yes/No)
18. I need to talk to a spiritual advisor (Yes/No)
19. I need to talk to people who have this same experience (Yes/No)
20. I need to be more reassured by my relatives (Yes/No)
21. I need to feel more useful within my family (Yes/No)

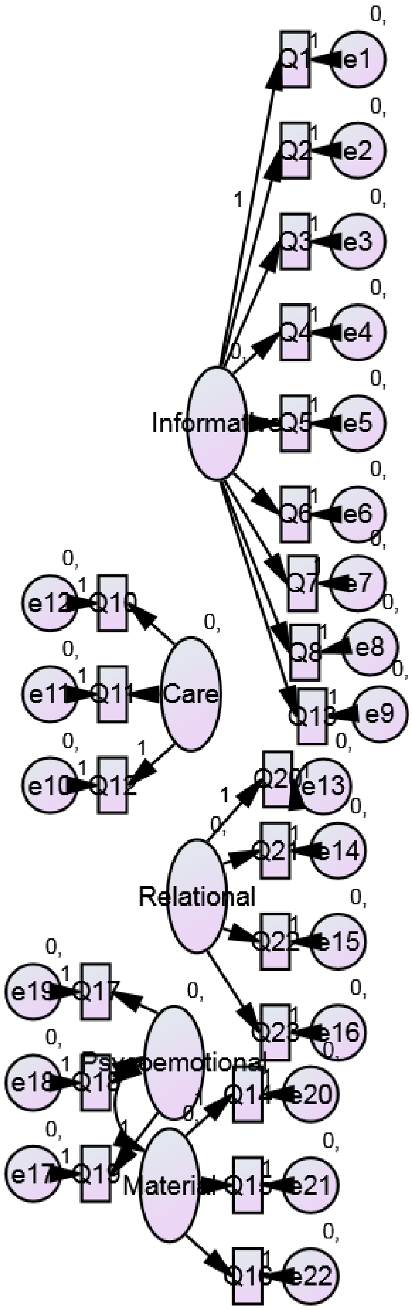
22. I need to feel less abandoned (Yes/No)

23. I need to receive less commiseration from other people (Yes/No)

## Figure 1

Schematic representation of CFA model for NEQ.

Note that correlations between latent constructs are not depicted in figure.



## Table 1

Cancer Treatment Experiences: Identified Themes

| Theme | Sub-theme | Private Healthcare | Public Healthcare |
|---|---|---|---|
| **Experience of treatment** | Positive | ✓ | ✓ |
| | Challenging (side-effects) | ✓ | ✓ |
| | No benefit | | ✓ |
| | Time Consuming | | |
| | • Receiving treatment | ✓ | |
| | • Waiting periods | | ✓ |
| | Concern/guilt about less fortunate | ✓ | |
| **Diagnosis** | Delay in diagnosis | ✓ | ✓ |
| | Shock/Relief | ✓ | ✓ |
| | Commencement of treatment | | |
| | • As soon as possible | | ✓ |
| | • Need more time before starting treatment | ✓ | |
| | Need for earlier diagnosis | ✓ | ✓ |
| **Preconceived ideas** | Fear of unknown | ✓ | ✓ |
| | Myths about treatment | ✓ | ✓ |
| | Individuality/unique treatment responses | ✓ | ✓ |

|  |  |  |  |
|---|---|---|---|
| **Information & communication** | Limited understanding prior to diagnosis | ✓ | ✓ |
|  | Well informed | ✓ | ✓ |
|  | Limited understanding due to medical terminology used | ✓ | ✓ |
|  | Uncertainty due to poor communication |  | ✓ |
| **Treatment decisions** | Included | ✓ | ✓ |
|  | Excluded |  | ✓ |
|  | Surrender final decision making to healthcare professional | ✓ | ✓ |
| **Changes resulting from treatment** | Financial burden | ✓ | ✓ |
|  | Lifestyle changes | ✓ | ✓ |
|  | New perspectives | ✓ | ✓ |
| **Coping strategies** | Metacognitive/Emotion-focused | ✓ |  |
|  | Practical/Problem-focused |  | ✓ |
|  | Religion | ✓ | ✓ |
| **Support system** | Appreciate support provided | ✓ | ✓ |
|  | Grateful for supporters | ✓ |  |
|  | Concern/guilt about impact on supporters |  | ✓ |
| **Medical aids** | Reduce financial burden | ✓ |  |
|  | Concern about depletion | ✓ |  |

| | | | |
|---|---|---|---|
| | Treatment not covered by medical aid | ✓ | |
| | Medical aid - superior treatment options | ✓ | |
| | Treatment should be equally accessible and more affordable | ✓ | ✓ |
| **Healthcare professionals** | | | |
| **Nursing staff** | Positive | ✓ | ✓ |
| | Incompetent/unprofessional | | ✓ |
| **Medical officers/ Oncologists** | Positive | ✓ | ✓ |
| | Limited time/accessibility | ✓ | |
| | No trust in abilities | | ✓ |
| **Research** | More research needed | ✓ | ✓ |
| **Changes needed in the treatment process** | Cultural/language issues | ✓ | ✓ |
| | Transport/travelling | ✓ | ✓ |
| | Increased treatment availability | ✓ | ✓ |
| | More treatment sites | ✓ | ✓ |
| | Elimination of side-effects | ✓ | ✓ |
| | Finding a cure | ✓ | |
| | Aesthetic improvements to treatment sites | ✓ | |
| | Gender equality regarding campaigns | ✓ | |
| | Increased productivity/efficiency | | ✓ |

|  |  |  |  |
|---|---|---|---|
|  | Staff competence |  | ✓ |
|  | Doctor continuity/appointment system |  | ✓ |

## Table 2

Statistical and practical significance

| Variable | Mean Private HC | Mean Public HC | p | Std. Dev. Private HC | Std. Dev. Public HC | Effect Size |
|---|---|---|---|---|---|---|
| **Informative** | 1.57 | 6.43 | <0.001 | 2.34 | 2.97 | 1.64 |
| **Assistance/care** | 0.30 | 0.87 | 0.02 | 0.65 | 1.07 | 0.53 |
| **Relational** | 0.83 | 2.13 | <0.001 | 0.95 | 1.57 | 0.83 |
| **Psychoemotional** | 0.77 | 1.40 | 0.03 | 0.94 | 1.25 | 0.51 |
| **Material** | 0.53 | 2.17 | <0.001 | 0.78 | 1.15 | 1.42 |

# Chapter 4: Article 3

## Manuscript: Healthcare professionals' experiences of working in oncology in the private and public healthcare sectors in the Eastern Cape, South Africa.

# Abstract

The multifaceted nature of cancer care requires multidimensional treatment with highly specialised professionals, equipment and services. Interdisciplinary cooperation focusing on patient-centred care is thus of the utmost importance. In a developing country such as South Africa competing healthcare care priorities, poor resources, cultural diversity, language barriers and the differential standards of treatment found in the private and public healthcare sectors, make an already complicated situation even more challenging. The aim of this study was to qualitatively explore healthcare professionals' perceptions and experiences of working in oncology by comparing the private and public healthcare sectors in the Eastern Cape, South Africa. A qualitative research design was followed. Forty healthcare professionals were purposively sampled from a government-funded hospital and a private treatment facility. Data was gathered by having the participants complete a self-report questionnaire. Analysis of the data yielded ten prevalent themes, namely general experience of working in oncology, most satisfying aspects of working in oncology, challenges and obstacles, coping strategies, information and communication, understanding of patients' perceptions and needs, wanting patients to understand, insufficient training, changes needed within the healthcare system and research. Both groups still appear to be following a mainly biomedical approach with minimal collaboration among multiprofessional team members. The majority of the differences experienced within the two groups can be traced back to the differing resources at their disposal. Addressing the above-mentioned discrepancies would require government involvement, allocation of funds, improved resources and additional training pertaining to psychosocial care.

**Keywords:** healthcare professionals, oncology, private sector, public sector, perceptions, experiences, South Africa

## Introduction

Cancer is a multifaceted disease, which can lead to impairment in a person's physical, social and emotional functioning (Beatty, Oxlad, Koczwara, & Wade, 2008), requiring multi-dimensional treatment with highly specialised professionals, equipment and services (Mathews, West, & Buehler, 2009). Working in oncology has been described as being similar to an expedition. Like climbing Everest, working in oncology involves thorough preparation, multidisciplinary teamwork, clear division of labour, intense work, considerable cost and plentiful rewards, immense obstacles, the need for replenishing and work that the general population cannot bear undertaking (Rohan & Bausch, 2009).

According to Adler and Page (2008), psychosocial care has been recognised by the Institute of Medicine as an essential component of comprehensive cancer care. Unfortunately the biomedical approach, which has traditionally been the foundation for healthcare throughout the world, often resulted in the psychological aspects of cancer being neglected as physicians focused solely on the inherent pathophysiological processes of the disease (Pillay, 2001). In recent years medical schools have tried to rectify this by incorporating dealing with the psychosocial aspects of patient care into their curriculum (Rohan & Bausch, 2009). Although the biopsychosocial perspective is generally accepted as being the best way to treat patients, in South Africa, the implementation of this strategy remains sadly lacking (Pillay, 2001). Lack of resources (Pillay, 2002), staff shortages (Maree & Wright, 2008), lack of knowledge and skill (Addington-Hall & O'Callaghan, 2009), large patient numbers (Bateman, 2011), cultural diversity (Wright, 1997) and language barriers (Mullin et al. 2000) are just some of the challenges healthcare professionals have to face on a daily basis. The above mentioned difficulties are even more prominent in the public healthcare sector (Bateman, 2011), where lack of feedback from referral hospitals and inadequate mechanisms of record keeping (Sibiya & Grainger, 2007) further exacerbates the problem.

Even without focusing on the psychosocial component of cancer care the sheer number of consultants and tests already involved in the diagnosis and treatment of cancer (medical, surgical and radiation) significantly impacts on the structure, process and outcome of care (Lee, Fitzgerald, Downey, & Moore, 2012). Traditionally, psychosocial problems are addressed by psychologists, psychiatrists and or social workers. These services are, however, not always available outside of large hospitals and urban areas, which led to the feasibility of other professionals, such as nurses, providing psychosocial support being explored. This approach, however, resulted in uncertainty about roles and responsibilities, challenging well-established territory between professionals (Arving & Holmström, 2011).

Healthcare professionals need to work as a well-functioning team where each has roles that are complementary specialised (Rohan & Bausch, 2009). Interdisciplinary co-operation focusing on patient-centered care is identified as one of the key aims for a high quality healthcare system (Institute of Medicine, 2001). This, however, requires intricate interaction between accessible and responsive healthcare delivery systems (Arora, Street, Epstein, & Butow, 2009), which in South Africa, especially in light of the above-mentioned difficulties, is no easy feat.

Further complicating the already stressful cancer treatment environment is the direct-to-consumer (DTC) advertising of prescription medications and the increased use of complementary and alternative therapies. Although some studies claim that DTC marketing encourages communication between healthcare professionals and their patients about various pharmaceutical products (Kravitz, 2000), some healthcare professionals reported feeling forced to comply with patients' requests when prescribing medications even if the requested drugs are not his/her first choice for treatment (Spurgeon, 1999). This leads to the concern that DTC advertising encourages prescriptions based on marketing strategies instead of evidence-based research (Viale, 2002). Although the DTC marketing of prescription medication is only legal in the United States and New Zealand (Mogull, 2008), this restraint appears to be merely theoretical in nature as advertisements and information available on the internet and in print media cross international borders with ease (Gray & Day, 2000).

The use of complementary and alternative therapies have also increased dramatically, with herbal medicines being the most common, together with homeopathy, vitamins/minerals, medicinal teas, spiritual therapies and relaxation techniques (Zanini et al. 2008). The South African Health Review of 2007 indicated nutritional supplements such as vitamins and minerals, herbal medicines, homeopathy and aromatherapy as being the complementary medicines and health products with the largest turnover at a consumer level (Gqaleni, Moodley, Kruger, Ntuli, & McLeod, 2007). Healthcare professionals, therefore, need to be aware of the fact that their patients are probably combining these agents with conventional treatment. Any complementary and/or alternative remedies used by patients should, therefore, be documented and monitored for possible interactions (Richardson, Sanders, Palmer, Greisinger, & Singletary, 2000).

In light of the complex and demanding treatment environment described above it is not surprising that the presence of burnout is well documented among oncology healthcare professionals (Poulsen, Poulsen, Khan, Poulsen, & Khan, 2011). Being continually confronted with illness, suffering and the potential of death on a daily basis creates an occupational milieu that can have a profound impact on the healthcare professionals working within this environment (Rohan & Bausch, 2009). Burnout is defined as a stress-induced syndrome consisting of three key factors: emotional exhaustion, depersonalisation and a lack of personal accomplishment (Maslach, 1976). It is well documented that high levels of burnout has a negative effect on the healthcare professional's quality of life and is associated with decreased treatment quality, increased medical errors, lack of empathy, and absenteeism (Blanchard et al. 2010). Various factors influence how healthcare professionals' experiences working in oncology. How healthcare professionals perceive factors such as the limits of medicine, feelings of helplessness (Quattrin et al. 2006), being of service (Rohan & Bausch, 2009), intellectual stimulation (Medland, Howard-Ruben, & Whitaker, 2004), personal growth (Van Rooyen, Le Roux, & Kotzè, 2008), culturally informed values and beliefs (Bettencourt, Talley, Molix, Schlegel, & Westgate, 2008), communication difficulties (Edwards, 2005), perceived lack of training (Addington-Hall & O'Callaghan, 2009) and patients' experiences will determine whether they experience their work as satisfying or stressful.

It is, therefore, important for healthcare professionals to take care of their own health and to have the necessary skills to manage the stressors associated with their work environment. Self-care strategies such as guided imagery, relaxation techniques, physical activity and mindful-breathing techniques have proved to be helpful coping strategies and can easily be adapted for use in the workplace (Edmonds, Lockwood, Bezjak, & Nyhof-Young, 2012). The use of effective stress management techniques can lead to increased awareness of self and others, thus creating a safer patient environment (Pipe et al. 2012).

One of the most prominent factors influencing a patient's experience of cancer is their perceptions and experience of treatment (Venter, Venter, Botha, & Strydom, 2008). Considering how complex and demanding the delivery of cancer treatment can be it raises the question how do healthcare professionals providing the treatment, experience this same occurrence?

## Research Aims

The aim of this study was to qualitatively explore South African healthcare professionals' perceptions and experiences of working in oncology by comparing the public and private healthcare sectors.

## Method

### Design

A qualitative research design was conducted, exploring the perceptions and experiences of healthcare professionals, with regard to cancer treatment and needs, working within the private and public healthcare sectors. The reason why the researcher chose to make use of a qualitative design is embedded in the fact that qualitative research looks at the range of experience, rather than the average experience (Neuman, 2003). The goal is, therefore, to discover existing truths and to provide a more complete understanding of reality. Qualitative researchers recognise that where human experience is concerned, the relevant reality is that which is experienced subjectively and in social context (Thorne, 2000). Uncovering knowledge about how the participating healthcare professionals think and feel about the circumstances in which they work, are thus more important than making judgements about whether these thoughts and feelings are valid. Even if a participants' view is not completely representative of the group within which he or she functions, their experience is still considered significant and can provide important insights for future research or for the development of treatment policies.

### Participants

Forty participants were purposively sampled from a private treatment facility and a government-funded hospital in the Eastern Cape. The researchers strived to include participants from as many of the healthcare professions involved in cancer treatment as possible.

The private healthcare group consisted of 18 healthcare professionals, one of whom was male and 17 female, ranging from 23 to 51 years in age. Twelve were White, three Coloured, two Black and one Indian. Ten identified their home language as Afrikaans, seven as English and one as being Xhosa. Healthcare professions represented by this group included one oncologist, two medical officers, two social workers, three administrative personnel, four radiation therapists and six nursing staff.

The public healthcare group consisted of 22 healthcare professionals, of whom three were male and 19 female, ranging from 26 to 65 years in age. Eight were White, seven Black, five Coloured and two Indian. Nine identified their home language as Afrikaans, six as English, six as Xhosa and one as being Zulu. Healthcare professions represented by this group included one oncologist, one social worker, one psychologist, two radiation therapists, two pharmacists, two administrative personnel, five medical officers and eight nursing staff.

Administrative staff were included in the study as they often work directly with the patients, making appointments and pulling files, and can offer a different perspective with regard to the non-medical aspects of treatment, focusing on structural or procedural issues.

### Data-gathering methods

Qualitative measurement was used during data collection. Participants were asked to complete a semi-structured self-report questionnaire consisting mostly of open-ended questions regarding the cancer treatment process (addendum 1). In an attempt to ensure that the questions, selected from the literature for inclusion in the questionnaire, were clear and effectively covered the cancer treatment process a pilot study was conducted. This involved working through the set of questions with two healthcare professionals and two cancer patients.

Participants were approached at their place of employment and asked to complete the self-report questionnaire. The questionnaire was made available in both Afrikaans and English, giving participants the opportunity to decide which they preferred. Conducting individual interviews were considered. In light of scheduling difficulties, based on the participating healthcare professionals' workload, as well as the rich data already obtained from the questionnaires, it was decided that it would be neither practical nor necessary for data saturation to be reached.

### Data Analysis

The data gathered by the self-report questionnaire was analysed making use of qualitative content analysis (Neuman, 2003). This process allows for the subjective interpretation of the content of text data. According to Hsieh and Shannon (2005), this is accomplished by the systematic classification process of coding and identifying themes or patterns.

In an attempt to gain a general understanding of what the participants were trying to express regarding the cancer treatment process, the researcher (first author) started by independently reading through the completed questionnaires. Once a general understanding was obtained, the text was then condensed into units of meaning, which were then discussed by the researcher and two other authors until a final categorisation of items were obtained. Initially the analysing process involved breaking down, examining, comparing, conceptualising and categorising the data. This is generally referred to as open coding (De Vos, Strydom, Fouché, & Delport, 2005). Open coding was followed by axial coding, which involved putting the data back together by identifying connections between the different categories. This was then taken one step further, making use of selective coding, by identifying core categories and how they relate to one another (De Vos et al. 2005). This process allowed the researcher to produce a qualitative description of the healthcare professionals' views on the cancer treatment process.

## Trustworthiness

According to Schmid (1981), qualitative research is the study of lived experiences as perceived by those under study. The following two underlying principles can be identified as being important in qualitative research. Firstly, it should be acknowledged that a person's physical-, cultural-, and psychological environment influences his or her behaviour and secondly, that behaviour often encompasses a lot more than that which is observed by the researcher. It is, however, these subjective meanings and perceptions of the research participants that are most significant in qualitative research. If a true picture is to be obtained these multiple realities need to be accessed and explored. It is, however, important to employ verification strategies to ensure the attainment of rigour when doing so, demonstrating the trustworthiness of the research study (Morse, Barrett, Mayan, Olson, & Spiers, 2002).

The researcher made use of Guba's model for assessing the trustworthiness of qualitative data (Guba, 1981). This model consists of the identification of the following four aspects: credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985). Various strategies, as proposed by Shenton (2004), were employed in an attempt to fulfil the above-mentioned criteria. To ensure credibility the researcher employed sound research methods, conducted a literature review on cancer research previously conducted in South Africa, and made sure to develop a familiarity with the culture of the participating organisations. According to Lincoln and Guba (1985), credibility requires adequate submersion in the research setting as this allows the participants to become accustomed to the researcher. It is believed that increased rapport may lead to participants volunteering more sensitive information, thus enhancing research findings. The researcher had also spend a significant amount of time at the participating organisations, first to obtain permission to conduct the study and then to collect data. According to Lincoln and Guba (1985), transferability is addressed if sufficient descriptive data is provided for comparative purposes. The researcher addressed this aspect by providing a comprehensive description of participants' biographical details and the research design used. Dependability considers the consistency of the data, whether the findings would be consistent if the study were to be replicated with the same participants or in a similar context. By providing an in-depth methodological description of the study, as well as the biographical details of the participants, the researcher describes the context of the study, which allows for the replication thereof should the need arise. It should, however, be noted that variability is often found in qualitative research. According to Guba (1981), this is considered acceptable as long as the variability can be tracked and ascribed to identified sources. The aspect of confirmability is concerned with the fact that research procedures and results should be unbiased (Lincoln & Guba, 1985). In an attempt to reduce investigator bias the researcher made use of triangulation. For example, there was constant collaboration between the researcher and the other two authors during every phase of the study. This process is believed to minimise possible bias and ensures that the methods used are employed correctly.

## Ethical Concerns

Permission to conduct the study (NWU-00125-11-A1) was granted by the ethics committee of the North-West University (Potchefstroom Campus). Participants were informed about the voluntary nature of the study and informed consent was obtained from all participants and relevant organisations prior to data collection. Release forms for the use of the data and publication of the findings were signed by all participants. Confidentiality and anonymity were attained by ensuring that no identifiable information was used during the results discussion.

## Results

Analyses of the data yielded ten prevalent themes (table 1) and are discussed below. Despite similar experiences being reported within the public and private healthcare sectors there were also prominent differences indicative of the unique environment within which each group operates. Themes one through four provide an overall view of working within an oncology environment, highlighting factors contributing to job satisfaction, challenges and obstacles experienced, and coping strategies employed. Themes five to seven focus on healthcare professionals' perceptions of certain aspects associated with cancer treatment, such as their views on the information provided to and communication with patients, their understanding of patients' perceptions of treatment and patients' needs, as well as what they wish patients understood. Themes eight and nine highlight deficits identified, focusing on areas for which insufficient training has been received, followed by proposed changes needed within the healthcare system. Theme ten concludes with healthcare professionals' perceptions of cancer research.

[place table 1 here]

### Theme 1: General experience of working in oncology

The majority of the healthcare professionals in both groups described working in an oncology setting as being a positive, yet emotionally challenging experience with plenty of opportunity for learning and personal growth. Comments made in this regard included: *"…enjoy working…"; "…very rewarding…"; "…good experience…"; "…stressful…emotionally draining…"; "…incredibly challenging…"; "…learned a lot…"; "…educational and informative…"; "…lots of intellectual stimulation…"; "…formed and shaped me as a person…"* and *"…life changing…wake-up call…life's a gift, appreciate it…"* Both groups also reported feeling that their work required a lot of responsibility. One healthcare professional expressed this as, *"…accuracy of treatment …very important…can cause death if staff is not focused…"*

Although working in an oncology environment can be difficult and poses many challenges, which will be discussed in theme three, it should be noted that none of the healthcare professionals participating, expressed extreme dislike or unwillingness to continue working in this setting. A minority of the healthcare professionals working within the private sector did, however, report feeling compelled to work in oncology, as they believed this to be their life's calling. One healthcare professional described this as, *"...ask myself every day, 'Why do I do this?'...I want to because I need to help these people...they need me...I am able to and I want to help them..."*

Myths about cancer treatment do not only affect cancer patients but can also influence inexperienced or uninformed healthcare professionals. One of the healthcare professionals working in the public sector admitted that it was her mistaken beliefs about cancer treatment that initially contributed to her reluctance to work in oncology. The following statement was made, *"...Initially I did not want to be in oncology…I had the misconception that you nurse people to die…working in oncology I've developed a passion for these patients…come to realise that there is a long road to walk between diagnosis and end-of-life…can make a difference in patients' lives…"*

### Theme 2: Most satisfying aspects of working in oncology

Both groups identified being of service and making a difference, seeing improvements in patients, being appreciated and the fact that their work was intellectually challenging and offered various opportunities for learning, as being the most satisfying aspects associated with working in oncology. Comments made in this regard included: *"...helping the patients...it gives you purpose...feel like you're making a difference..."; "...very rewarding when a patient responds to treatment...even little improvement makes a great difference..."; "...seeing the results...when patients come back years down the line and they are doing well..."; "...gratitude and positive feedback you get from patients..."; "...gaining knowledge and skill..."* and *"...intellectual stimulation..."*

A minority of the public sector healthcare professionals reported finding all aspects of their work satisfying. The following statements were made: *"...find it satisfying from the minute a patient has been diagnosed, obtaining consent from the patient, explaining the whole process…to seeing the patient…accepting to be treated…"* and *"…all…I enjoy my work whether I am working on the floor or doing the admin…"*

### Theme 3: Challenges and obstacles

Despite one of the healthcare professionals in the private sector stating, *"...fortunately we don't have any…we have a wonderful, comprehensive system and environment in which you can perform your duties…"*, a lack of resources and work overload due to high patient numbers were reported as being the most prominent challenges faced by those working in the public sector. A shortage of staff, funds, equipment and drugs were mentioned. Some of the comments made in this regard included, *"…too few competent staff…"; "…budget constraints…"; "…out-dated IT and administration systems…"* and *"…limitations in access to treatments that are new and expensive…"* High patient numbers coupled with the above-mentioned lack of resources result in long waiting times and work overload. Only a minority of the healthcare professionals in the private sector reported patient numbers and the accompanying workload as being problematic. One of the statements made in this regard was, *"…there is never enough time to spend with the patients…"* The effect of limited resources coupled with high patient numbers appears to be far reaching in the public sector as can be seen by the following statements made, *"…large number of patients…lead to late scans…and screening test dates…causes delays in treatment…"; "…waiting list for radiation…"; "…long waiting times are a real challenge…"* and *"…have to go beyond my duties…take patients home…deliver their medication…"*

Patients' lack of resources also adds to the frustrations experienced by healthcare professionals. A minority of the healthcare professionals in the private sector reported this as being an obstacle to administering treatment. Statements made included, *"...patients' financial and logistical issues are often obstacles…"* and *"...treatment is very* *expensive…affect finances…some people leave their jobs because they need to be on treatment fulltime…"* The majority of the healthcare professionals in the public sector reported patients' lack of resources as being problematic to treatment. Some of the comments made included the following, *"…some are diabetics…no money to buy food…"; "…transport…money problems…cause patients to default their treatments…"* and *"…patients that come with the ambulances from neighbouring towns often miss their transport because of long waiting times…"*

Healthcare professionals, from both groups, reported experiencing patients' cultural beliefs and lack of understanding as being obstacles to providing effective treatment. Comments made in this regard included, *"…fear of radiation…use traditional medicines…"; "…challenge to counter myths about side-effects…"* and *"…cultural and educational level divide…makes for miscommunication…"*

The majority of the healthcare professionals, in both groups, reported having to deal with patients' emotions, as being a challenge. A few of the remarks made included, *"…emotional states can often impede the course of treatment…"; "…very impatient and depressed…"; "…sometimes one doesn't really know how to approach them…"* and *"…you carry the emotional aspects of each patient…can be difficult to separate your professional side from the emotional side…"*

The minority of the healthcare professionals, in both groups, also experienced patients' families as potential obstacles to providing treatment. Comments made regarding the difficulties experienced with patients' families included, *"…sometimes the families of patients are in need of more care…financially…emotionally…socially…that I struggle to meet…"; "…families are also a challenge in many ways…interfere and cause patients to be very anxious…"* and *"…families put pressure on them to receive or not receive treatment…"*

The complexity of the field of oncology, the inevitability of death, as well as language barriers were identified by the minority of the healthcare professionals, in both groups, as being challenging. Some of the statements made included the following, *"…questions…sometimes difficult to answer…"; "…every patient is an individual with different cancers and different circumstances…treatment is very individualised…"; "…dealing with constant life-threatening diseases and having to communicate the mortality of the condition…" ; "…difficult to tell patients there is nothing more you can do…"* and *"…difficult for you to understand the patient…difficult for the patient to understand the instructions…"*

Administrative responsibilities were identified by a minority of the healthcare professionals, in both groups, as a major hindrance. Comments included, *"...most problematic part of my work is dealing with an inadequate administration…"* and *"...amount of administrative responsibilities…hours of work exhausting…"*

Struggling with patients' medical aid schemes and the lengthy authorisation and motivational procedures required were identified by healthcare professionals in the private sector as being an obstacle to providing fast and effective treatment. Comments made included, *"...medical aids refusing to pay for certain treatments...take long to authorise treatment..."* and *"...medical aid limitations...affordability of newer treatments a problem..."*

Work politics and patients' unhealthy lifestyle choices were identified by a minority of the public sector group as being obstacles to providing effective care. Statements made included, *"...autocracy…those in charge is an obstacle…"* and *"...poor hygiene…smoking and alcohol abuse…causes problems in treating patients effectively…"*

**Theme 4: Coping strategies**

Although healthcare professionals, from both groups, admitted to not always taking care of themselves adequately, they did identify the need to take care of one's physical and mental health as being of the utmost importance. Both groups indicated the need for improved personal care with statements such as, *"…need to take care of the caregivers too…"* and *"…take sufficient care of your own needs…"*

Healthcare professionals in the private sector group suggested more counselling and debriefing, and also indicated a need for more leave days. Comments included, *"...there need to be regular counselling sessions…you don't know what you haven't dealt with until you're forced to talk…"* ; *"…value the need for debriefing…"* and *"...should give us more leave days…can be emotionally draining at times…"*

Healthcare professionals in the public sector group identified peer support and the need to cultivate an open mind and trust in one's own abilities as being important coping strategies. Statements made, included the following, *"...consult with other professionals when under stress to seek solutions…"; "…believe in yourself and your capabilities…"* and *"…be open to advice…use your sixth sense to stay alert…"*

**Theme 5: Information and communication**

While the majority of the healthcare professionals in the private sector group felt that the information provided and the opportunities for communication with patients were sufficient, the majority of the public sector group reported it as being insufficient. The following comments were made respectively, *"…we offer the support necessary…patients do get information brochures…see our social workers…as doctors we try and communicate well…offering advice and support rather than being authoritarian…"* and *"…not enough information is given to patients by all the healthcare professionals involved in the treatment process…"*

Both groups identified patient capabilities, time constraints, language barriers and cultural diversity as influencing the quality of the information provided and communication opportunities. All four of these factors were identified previously in the theme 'challenges and obstacles' as impediments to providing effective treatment and as detracting from healthcare professionals' working experience. Comments made in this regard relating to information and communication opportunities include, *"...patients do not always fully understand their illness and the importance of complying…do not have good insight…need to come down to the level of the patient's understanding…"; "…communication opportunities with patients are restrained with regards to time…because of the large number of patients having to be served...patients and doctors alike feel pressured…"; "…the nature of the information is fairly technical and needs explanation...difficult, especially with language limitations in what is sometimes an emotionally charged interview…"* and *"…difficult to get patients to believe us…especially when already misinformed by cultural beliefs and fear of the unknown…"*

### Theme 6: Understanding of patients' perceptions and needs

The majority of healthcare professionals, in both groups, believe that patients perceive actively receiving treatment as being the most beneficial aspect of cancer care. Comments made in this regard include, *"…actual medical treatment gives them hope that their condition will improve…"; "…once they're on treatment they become more relaxed…"* and *"…medical management of their disease…"*

A minority of the healthcare professionals, in both groups, believe symptom control, emotional support and receiving information to be what patients perceive as most beneficial. Statements made included, *"...symptom control…seen as beneficial as symptoms tend to be extreme…"; "…that you're always there for them…that you listen and reassure them…generally value the amount of TLC they receive…"* and *"…information sharing…explanation of disease and treatment prognosis…"*

A minority of the healthcare professionals, in the private sector group, believe that what is perceived as most beneficial varies according to patients' characteristics and circumstances. Comments made included, *"...different from patient to patient…"; "...difficult to say as each type of cancer is treated differently…"* and *"...it depends on their cultural beliefs and background…the level of information they have received…"* A minority of the healthcare professionals in the public sector indicated supportive social services as being what they think patients find most beneficial. One of the statements made were, *"…access to supportive services…such as help with obtaining a disability grant…"*

Information, empathy and understanding, symptom control, respect, cure and the provision of hope were identified by healthcare professionals, in both groups, as being what they believe patients want from them the most. Healthcare professionals working in the public sector also identified professionalism, competence and assistance with social aspects as being what they believe patients need from them the most. Some of the comments made included, *"...to be treated appropriately and professionally…"; "...fast and efficient service…"; "…to be booked off from work…"* and *"…transport assistance…"*

**Theme 7: Wanting patients to understand**

Healthcare professionals, in both groups, wished that patients were able to understand and accept the following: they are doing their best, there are no guarantees, treatment is time-consuming, patients need to take responsibility for their own health, and for patients to have the ability to grasp the information provided.

While those in the private sector wanted patients to understand that they are doing their best to serve everyone, as every patient is equally important, those in the public sector wanted them to understand that they are doing their best given the limited resources at their disposal. The following comments clearly illustrate this distinction, *"…everybody needs to realise that everyone's needs are equally important and that we need to give the same attention to everyone…"* and *"...there is one machine and one treatment bed and you can't put two people on one bed at the same time...patients are very impatient...adds to the stress of the staff…"* Some of the other comments made about what healthcare professionals want patients to understand regarding treatment included: *"…wish that they would understand that this is not foolproof treatment…"* and *"...proper treatments and exams take time...slow process, there is no quick results…"* While only a minority of the healthcare professionals in the private sector indicated the need for patients to take responsibility for their own health, the majority of those in the public sector indicated this need. Some of the statements made in this regard included, *"…treatment…requires input from patients…"* and *"…responsible for own choices until the end…"* As previously mentioned healthcare professionals from both groups indicated a need for patients to have a better grasp of the information given to them. Comments made in this regard included, *"…understand and have insight into their illness…"* and *"…diagnosis, treatment and prognosis…they often do not seem to quite understand or internalise those…"*

Healthcare professionals in the private sector also indicated a need for patients to appreciate the fact that they are unique individuals and that even though all of them have cancer each case is still unique. One of the statements made was: *"…everybody is different, don't think that because a distant relative or someone had struggled with their treatment that you are going to…every cancer is treated differently…side-effects differ according to the treatment…"*

### Theme 8: Insufficient training

Despite the fact that a minority of the healthcare professionals, in both groups, indicated that there was no area of cancer care for which they felt ill-prepared the majority of both groups reported the need for further training pertaining to various areas of oncology. Healthcare professionals in the private sector primarily indicated a need for continuous skills development, as well as the need to keep abreast of new developments in the field while some of those in the public sector expressed a need for even the most basic oncology training. Comments made in this regard included, *"…there is always more knowledge needed…in all aspects of this field…"; "…keeping informed about evidence based medicine is a continuous process taking up extensive time…"; "…it is demoralising to work in a special department without the qualification…you are doing the same job, but you don't get the benefits…"* and *"…both chemo and radiation therapy, as neither modality was highlighted on in the medical school curricula…exposure to oncology patients during undergraduate training was mostly limited to hospice patients for symptom control…the exposure to chemo- or radiation therapy was non-existent…"*

Both groups indicated the need for more training of a multi-professional nature, what each professional's role is and how it all fits together. Some of the comments made, included, *"…I would like to know more about what is going on in each department…"* and *"…we are sufficiently trained in our field but not able to assist with other fields working very close to us…"* Both groups also indicated a need for training in providing psychological care, *"…definitely to give patients' emotional support…the 'counselling' or emotional* *encouragement that they need…feel as if I am blubbering nonsense…that it is not adequate…"*

One of the healthcare professionals in the public sector also indicated a need for training in financial management.

**Theme 9: Changes needed within the healthcare system**

Although a minority of the healthcare professionals in both groups indicated that there are no changes needed in the current treatment process, the majority of them had numerous suggestions for how treatment could be improved. While the majority of the improvements suggested were similar for both sectors, there were also suggestions made that were distinctive to the private- or public healthcare sector, respectively.

Both groups reported improvements needed in the following areas of treatment: provision of education and information, multi-professional team cooperation, funding, as well as providing patients with social assistance. Both groups felt very strongly about education and the provision of information, believing that it will lead to earlier detection and thus improved treatment outcomes. Statements made in this regard included: *"…to have information available in all eleven official languages…"; "…more outreach and education, focusing on cancer, signs and symptoms so that we can prevent and start treating from early stages…"* and *"… prevention – requires a knowledgeable population…"* Healthcare professionals, in both groups, also indicated a need for more cooperation between the different professions involved in cancer treatment. Comments made included, *"…early contact between surgical and oncology departments so that a treatment decision is jointly agreed upon, before surgery is instigated…"* and *"…patients must be seen holistically before any decisions are made...meeting where all is present: doctor, surgeon, social worker, dietician, etc…"* Changes with regard to the funding of cancer treatment were also indicated by both groups. While those in the private sector indicated a need for funds to be distributed differently, those in the public sector reported the need for more funding, as well as for the improved monitoring of funds. One of the statements made by the private sector group included: *"…the money that goes to cancer organisations…used to the benefit of patients and not only to pay salaries…"* while comments made in the public sector included: *"…more funding is needed to have better cancer drugs and treatments available…"* and *"…the department of health has already started a process of improving equipment…but the finances often vanish…"* Providing patients with improved social assistance was also reported by both groups. While those in the private sector indicated a need to assist out-of-town patients and their families with accommodation, healthcare professionals in the public sector felt that patients also required additional assistance with transport and nutrition. One of the comments made in the private healthcare group was, *"…a private hospital especially for cancer patients…where families can reside in chalets…"* Comments made in the public sector included, *"…provision of boarding facilities for out of town and needy patients…because lack of this result in non-adherence as patients stay away…"; "…have patients from the country…misses treatment due to transport problems…"* and *"…providing food for patients while they wait…"*

Changes specifically indicated by the private sector group included: less interference from medical aids, treatment equality, an effective cancer registry and finding a cure. Comments made in this regard included, *"…time patients have to wait for approval of their treatment…the fact that medical aids sometimes want to decide what treatment the patient should get…"; "…medical aids not be so prescriptive when it comes to their requirements for codes, copies and repetitive requests for motivations for everything…"; "…make treatment more accessible to all cancer patients…private and government patients…"; "…well-functioning cancer registry…"* and *"…to find a cure…"*

Changes specifically indicated by the public sector group included the need for increased productivity and efficiency as it is believed that this will decrease waiting times, alleviating some of the pressure caused by high patient numbers. Suggestions made for increased productivity and efficiency included appointing more staff, increasing staff competence, having treatment protocols in place, updating resources and increasing the number of available treatment sites. Comments made included: *"…there is always a shortage of staff…more doctors need to be appointed…more specialist oncologists practicing in the country…"; "…keeping doctors in touch with latest treatment available…continuous education…on side-effects and indications…"; "…effective protocols…relieve pressure from the consultant…currently all treatment decisions are made by consultant…"; "…buy more machines and equipment for management of cancer…"* and *"…in the state sector facilities and specialists able to administer cancer treatment needs to increase drastically…"*

Two of the healthcare professionals in the private sector, with previous experience working in the public sector, raised various concerns regarding the treatment within each of these environments. The following comments were made: *"…main concern is that they have fallen far behind the standards attainable in private oncology…private treatment is extremely expensive, but we offer responses not attainable in state, with resulting improvements in overall survival and quality of life…"* ; *"…worked at [state] hospital…I was horrified by the* *experience…equipment was outdated…health workers were overwhelmed…there were no systems in place and no computer record-keeping…it seemed to be endless 'file searching and shuffling'…"* and *"…in private practice I am increasingly starting to become despondent about patients being treated because they can afford it…we will be [treating] the patient till the day they die…sometimes it is the family that doesn't want to stop, but often it is the oncologist that insists we carry on…"* One of the public sector healthcare professionals also indicated being concerned about over-treatment, *"…stop over-treating incurable patients…with expensive medication…"*

### Theme 10: Research

Both groups reported the need for more research to be conducted, *"…not enough research is being done in this country…"*, and for government involvement, *"…government to make funds available…to invest in cancer research…"*

Comments made by the private sector indicated a need for research in neglected areas with serviceable recommendations. One of the statements made in this regard included, *"…research about cancer incidence, perceptions, treatment in rural/under-serviced areas…with realistic recommendations…"*

Although the public sector reported the need for research to focus on prevention and early detection, they also indicated a need for research to focus on the improvement and use of treatments currently available. Comments made included, *"…extensive attention to prevention and early diagnosis…"; "…improvement in the chemotherapy drugs…"* and *"…strive towards evidence based medicine…"*

## Discussion

The field of oncology differs in many ways from other areas of healthcare, yet its uniqueness is seldom appreciated outside of this field (Van Rooyen et al. 2008). The multifaceted nature of cancer care (Beatty et al. 2008), place various demands on healthcare professionals, which is often experienced as being stressful and emotionally demanding (Mohan, Wilkes, Ogunsiji, & Walker, 2005). Working in oncology has been described as being on the front line of a war against death, requiring the synchronisation of numerous intricate tasks (Cohen & Sarter, 1992). Despite this clearly challenging work environment, a study conducted by Rohan and Bausch (2009) indicated that healthcare professionals often experience the positive aspects of oncology work as mostly overshadowing the challenges related with this field. This was also evident in the current study, as both groups reported working in oncology as being a positive, yet emotionally challenging experience, offering plenty of opportunity for learning and personal growth with none of the participants indicating an unwillingness to continue working in this setting. Similar results were found by Quattrin et al. (2006), who reported that not only did the majority of their participants choose to work in oncology, they also indicated a desire to remain working in this field.

In spite of the positive work experiences reported, healthcare professionals employed in oncology are exposed to high levels of work-related stress (Quattrin et al. 2006). Being confronted with death and dying on a daily basis, coupled with feelings of helplessness associated with the limitations of treatment can be emotionally draining (Quattrin et al. 2006; Blanchard et al. 2010). According to Fallowfield, Ratcliffe, Jenkins, and Saul (2001), studies in the United Kingdom and United States indicated psychiatric morbidity and emotional burnout as being almost similar in prevalence among oncologists and cancer patients. The positive side of this complex working environment is that it offers plenty of opportunity for learning and personal growth. Realising how precious and fleeting life is, increased healthcare professionals' appreciation of their own lives. Rohan and Bausch (2009), describe this paradoxical field of cancer care as being 'both sad and uplifting at the same time'.

A minority of the healthcare professionals in the private sector group reported working in oncology as being their life's calling. Despite all the sadness and suffering, they felt compelled to work in this environment, believing that they can make a difference. According to Van Rooyen et al. (2008), this passion for working in oncology cannot be taught. How these healthcare professionals conduct their work is determined by their life philosophies and, in turn, these philosophies are shaped by their work experiences. Inexperienced healthcare professionals can, however, be daunted by the prospect of having to work in an oncology ward. Perceived lack of preparation to provide care for patients with cancer may lead to healthcare professionals avoiding working in this field. It is often only through practical experience (Copp, Caldwell, Atwal, Brett-Richards, & Coleman, 2007), that healthcare professionals come to realise that being an oncology nurse is less about dying and more about living, providing them with a unique opportunity to assist cancer patients on their treatment journey (Medland et al. 2004).

Healthcare professionals in both groups identified numerous aspects of working in oncology as being gratifying and rewarding. In concurrence with the present study, Rohan and Bausch (2009), also identified the easing of patients' suffering and patient gratitude as being components of care that were considered as being most rewarding. Improvements in patients were also experienced by healthcare professionals as being a source of work satisfaction. Seeing patients improve, may act as a type of validation, creating a sense of purpose and providing strength and hope to be drawn upon when being confronted with death and dying on a daily basis. The complex and challenging work associated with cancer care provides healthcare professionals with the opportunity to rise to the challenge in order to meet the complex needs oncology patients have. This is not only intellectually challenging, but it also proves that they have the necessary skills needed, thus creating a sense of pride and satisfaction. According to Medland et al. (2004), the field of oncology offers plenty of opportunity for this, as it is often challenging, intellectually stimulating and provides an environment for lifelong learning. The fact that a minority of the public sector healthcare professionals reported finding all aspects of their work satisfying can possibly be related to the sentiment of Van Rooyen et al. (2008), that a true passion for working in oncology cannot be taught. Like the healthcare professionals from the private sector, whom indicated working in oncology as being their life's calling, these healthcare professionals find no aspect of their work too challenging or too mundane.

The intricacy of cancer treatment, coupled with the number of professionals required for holistic care to be achieved (Lee et al. 2012), highlights the fact that providing effective care is clearly going to be challenging. In a developing country such as South Africa competing healthcare priorities (Michelow, McKee, & Hlongwane, 2006), poor resources (Pillay, 2002), cultural diversity (Wright, 1997), language barriers (Mullin et al. 2000) and the differential standards of treatment found in the private and public healthcare sectors (Bateman, 2011), make an already complicated situation even more challenging. While lack of resources was not mentioned as being a problem by the healthcare professionals in the private sector group the majority of those in the public sector reported lack of resources, high patient numbers and the resulting work overload as being the most prominent challenges when it came to providing effective treatment. The resources identified as lacking included staff, funds, equipment and drugs. When you add this lack of resources to an ever-increasing demand for treatment, you are left with long waiting times and overworked healthcare professionals, who are simply unable to meet the public's healthcare needs. According to Grunfeld et al. (2004), this problem could have been anticipated as the growing demand for cancer treatment has not been consistently matched with a corresponding increase in human and technical resources. The fact that the above-mentioned scenario was primarily reported by the public sector group, with only a minority of the private sector group indicating how high patient numbers and workload impacted on the time allocated to each patient, once again confirms the treatment gulf that exists within the South African healthcare sectors (Bateman, 2011).

Adding to the already limiting effect of minimal treatment resources are the patients' lack of resources. While this was mentioned by only a minority of the private sector group, the majority of the public sector reported patients' lack of resources as impeding treatment. A possible explanation for this differing experience can be found in the fact that private sector patients often enjoy a higher socioeconomic status than those forced to receive public sector care, and thus have access to more personal resources, which could potentially ease their treatment experience. While those in the private sector mentioned logistical issues and the impact of treatment on patients' financial status, healthcare professionals in the public sector indicated patients not having any money to buy food and defaulting treatment due to transport problems. Defaulting treatment and lack of proper nutrition, especially while actively receiving cancer treatment, can have a detrimental effect on treatment outcomes. Malnutrition almost always leads to immunosuppression and if a patient's immune system is to be expected to fight cancer cells and cope with treatment side-effects, it needs to be provided with the nutritional prerequisites to react optimally for the best possible therapeutic results to be obtained (Barker et al. 2013). In South Africa, cancer treatment is only available in its major centres. The costs incurred by treatment-related traveling thus adds to the economic burden patients are already experiencing (Anderson, Goldberg, Algar, Felix, & Ramesar, 2007). Defaulting treatment is thus often a direct result of patients' inability to cover the costs associated with the travelling required in order to receive treatment.

The multi-ethnic nature of South Africa requires healthcare professionals to be aware of the fact that patients' culturally informed values and beliefs may influence their disease perceptions and behaviours (Bettencourt et al. 2008). According to Lourens (2013), these beliefs are, however, often perceived as barriers influencing the attainment of suitable healthcare. Taking into account South Africa's unusually diverse population there is an increased likelihood of treatment situations where the healthcare professionals and patients stem from different cultural backgrounds (Pfaff & Couper, 2009). Therefore, even if healthcare professionals are aware of the cultural values underpinning patients' beliefs, this understanding is often little more than theoretical in nature and patients' resulting behaviours are thus still experienced as being counterproductive to treatment. In turn, patients might feel misunderstood and distrust healthcare professionals' efforts to treat them. This is especially significant in light of Kelly, Ghazi, and Caldwell's research (2002). They reported that when patients perceive healthcare professionals as being supportive of their ideas and feelings, it allows for the maintenance of hope.

Patients' inability to understand the disease and treatment-related information given to them was also report by both groups as being an obstacle to providing quality care. Patients are expected to understand and integrate the multifaceted medical- and psychosocial information provided to them (Fischhoff, 1999). According to Schlebusch (1990), patients are often only given minimal information as they are perceived as being incapable of understanding significant details about their illness. Pillay (2001), is of opinion that this practice actually increases patients' feelings of anxiety and insecurity. A study conducted by Masalla, De Waal, and Friedrich-Nel (2010), however found that illiterate and semi-literate patients, even after several consultations and interventions, still had difficulty understanding or showed a complete lack of understanding any of the disease and treatment-related information provided. Given the Eastern Cape's vast illiteracy, where 23% of the population age 20 years and older have had no formal schooling (Statistics South Africa, 2003), this is bound to be a problem. According to Voorhees et al. (2009), healthcare professionals need to provide information in such a way as to align patients' perceptions with reality, which in light of the cultural differences discussed earlier, leads one to the question, 'who's reality?'

The majority of healthcare professionals, from both groups, indicated having to deal with patients' emotions as being a challenge. According to Rehse and Pukrop (2003), cancer patients often experience a significant level of psychological distress and the provision of psychosocial support thus plays a crucial role in alleviating patients' suffering. Unfortunately psychosocial needs are frequently unmet in cancer patients (Sharpe, Butow, Smith, McConnel, & Clarke, 2005). Some healthcare professionals have even been identified as using distancing strategies when patients try to disclose psychological concerns and related feelings for fear of getting into 'deep water' about emotional issues (Maguire & Pitceathly, 2003). Numerous reasons were given for the use of distancing strategies. Some healthcare professionals reported a fear of probing, believing that they would be unable to contain patients' unleashed emotions or that they would become too involved emotionally and identify with the patient's suffering (Maguire & Pitceathly, 2003). These fears were also identified by healthcare professionals in the current study, reporting that it was sometimes difficult to separate a person's professional side from the emotional side. Healthcare professionals in the present study also reported not always knowing how to approach these situations. This sentiment is shared by other studies reporting a lack of confidence and training in the communication skills needed to handle difficult questions and uncertainties as being the underlying reason for healthcare professionals distancing themselves from patients' emotions (McDonnell, Johnston, Gallagher, & McGlade, 2002; Maguire & Pitceathly, 2003). In light of the above-mentioned it is clear that healthcare professionals experience the provision of psychosocial support as being an especially challenging aspect of treatment (Turner et al. 2005), which is quite concerning considering Pålsson and Norberg's (1995) study, where patients reported the presence of a comforting healthcare professional who listened and accepted their emotions as alleviating anxiety about their disease.

A minority of the healthcare professionals, in both groups, also indicated having to deal with patients' families as being challenging. The effect of cancer goes far beyond the patient, impacting entire family units (Manicom, 2010). Patients' families are often their main support system and their opinions thus contribute heavily to patients' experiences (Venter et al. 2008). Unfortunately, the difficulties family members' experience regarding acceptance and coping with the treatment process is often perceived by healthcare professionals as obstacles to providing patient care. In a study conducted by Beckstrand, Moore, Callister, and Bond (2009), on oncology nurses' perceptions of obstacles and supportive behaviours at the end of life, nine of the top 12 obstacles identified were directly related to patients' families. Considering the high patient numbers and lack of resources South African healthcare professionals, especially in the public sector, cannot be expected to deal with family members when they barely have the man power to adequately care for the patients. It is, therefore, important for healthcare professionals to recognise that even though patients' families need to be a part of the process, the patient remains their main priority.

Other challenges identified by a minority of both groups included the complexity of oncology work, the inevitability of death, language barriers and administrative responsibilities. Having to explain the intricacies of the treatment process, especially in light of the cultural and educational divide discussed earlier, poses a challenge for some healthcare professionals. Difficulties reported with regard to the inevitability of death could be related to the fact that some physicians and nurses may find discussing end-of-life topics uncomfortable (Edwards, 2005), especially if one takes into account their inability to cope with patients' emotions. Another explanation of this could be that healthcare professionals lose their perceived control over the disease process (De Haes & Koedoot, 2003), destroying their sense of purpose and diminishing hope. This is especially significant as the concept of hope has been identified as helping healthcare professionals to provide comfort, build rapport and communicate with terminally ill patients and their families (Duggleby & Wright, 2007). Apart from the communication difficulties already discussed, the presence of a language barrier often further complicates an already difficult situation. As a country with 11 official languages many healthcare professionals need to deal with this on a daily basis (Venter, Venter, & Botha, 2012). With only one healthcare professional in the private sector and six in the public sector indicating their home language as being Xhosa, language-related difficulties could have been anticipated since the majority of the population in the Eastern Cape reports this as being their home language (Statistics South Africa, 2003). The challenge presented by administrative responsibilities was primarily due to a lack of adequate resources in the public sector and due to time constraints in the private sector. Both groups were of the opinion that if administrative tasks could be dealt with in a more efficient and less time-consuming way, then more time could be allocated to treating patients.

Adding to these administrative responsibilities, healthcare professionals in the private sector reported the additional challenge of having to deal with patients' medical aid schemes. The lengthy authorisation and motivational procedures required, as well as the often prescriptive nature in which medical aids authorise treatment, were perceived as being an obstacle to providing fast and effective care. Studies have found that patients belonging to a medical aid scheme often present for treatment at earlier stages in disease development (Vorobiof, Sitas, & Vorobiof, 2001). Ironically, once treatment commences, it is often also the medical aid schemes that are responsible for slowing down the treatment process. Altilio (2006), indicated this same problem stating that medical insurers not only question prescribers, but they also put restrictions on the selection of medications and dosages allowed. Considering the high incidence of medical aid fraud and abuse one cannot really blame medical aids for taking protective measures. According to Campbell, Quigley, Collins, Yeracaris, and Chaora (2001), common fraudulent activities range from beneficiaries providing non-members with their medical aid details, leading to inappropriate billings, to healthcare providers submitting unrealistically high volumes of visits per day, which leads one to suspect fraud and/or poor quality of service. Even if justified, the fact remains that the required medical aid procedures often result in terminally ill patients having to suffer or receive less effective care.

A minority of the healthcare professionals in the public sector also indicated work politics and patients' unhealthy lifestyle choices as being obstacles to treatment. One of the comments made, indicated management as being an obstacle. This experience was also reported by Fallowfield, Saul, and Gilligan's study (2001), where difficulties with colleagues and the absence of supportive management were identified by oncology nurses as being a problem. This is especially concerning as Kenny, Endacott, Botti, and Watts (2007), indicated supportive management as being a key component for the provision of quality cancer care. Patients' unhealthy lifestyle choices, such as smoking and alcohol use, were bound to be considered by healthcare professionals as being an obstacle to treatment. Patients who smoke or abuse alcohol are more likely to display other unhealthy habits, such as poor diet and an increased use of analgesics, which can lead to immunosuppression, predisposing patients to a more rapid progression of cancer (Oh et al. 2000).

According to Medland et al. (2004), optimal care starts with caring for the caregiver. In order for healthcare professionals to provide effective care they need to receive nurturing and emotional support (Boyle, 2000). Both groups indicated the importance of taking care of their own physical and mental health as being of the utmost importance. This is supported by Quattrin et al. (2006), who indicated healthcare professionals caring for their own health as being an important buffer for work-related stress. Physical activity and routine medical examinations were indicated. Healthcare professionals in the private sector group also reported a need for more counselling and debriefing, as well as more leave days. This is supported by Edmonds et al. (2012), who is of the opinion that regular debriefing sessions, focusing on dealing with vicarious trauma and loss, has the potential to improve emotional exhaustion in medical professionals. Having more leave days would award healthcare professionals the opportunity to recharge away from their challenging work environment. This sentiment is supported by Quattrin et al. (2006), who indicated that healthcare professionals who participate in activities that make them feel better often mitigates the experience of workplace stressors. Healthcare professionals in the public sector indicated peer support and cultivating an open mind and trust in one's own abilities as being important coping strategies. Support groups and coaching by experienced physicians have been proven to reduce burnout, improving healthcare professionals' well-being and attitudes towards patient-centered care (Blanchard et al. 2010).

Patient-centered care involves taking a holistic approach to treatment (Arora et al. 2009; Masalla et al. 2010). According to Kvåle and Bondevik (2008), patient-centered care involves treating patients with respect, being honest in the provision of information and communicating with them in such a way as to make them feel valued and included in treatment decisions. While the healthcare professionals in the private sector group perceived the information provided and the opportunities for communication with patients as being sufficient, those in the public sector group reported this aspect of care as being mostly insufficient. Both groups did, however, indicate the same factors as influencing the quality of the information provided and communication opportunities. These factors, as previously discussed, included patient capabilities, time constraints, language barriers and cultural diversity. Various studies have indicated healthcare professionals as lacking communication skills and being in need of communication skills training (Maguire & Pitceathly, 2003; Royak-Schaler et al. 2006; Voorhees et al. 2009). The current study, however, indicated that, in this case, it was not a lack of communication skills per se, but rather a mismatch between patients' characteristics (culture/language) and those of the healthcare professionals. When combining this mismatch with time constraints, due to lack of resources and work overload, the resulting situation is one in which even the most skilled conversationalist would be hard pressed to provide effective information and communication. As previously mentioned, these obstacles are more prevalent in the public sector and could, therefore, explain why the healthcare professionals in this group reported having more difficulty. The fact that healthcare professionals are aware, and admit to this deficiency should, however, be seen as being a positive aspect for it is not ignorance that sustains the status quo but rather a lack of resources.

In order for healthcare professionals to meet patients' needs, they first need to be aware of what patients perceive as being most beneficial. The majority of the healthcare professionals, in both groups, believe that patients perceive active treatment as being the most important aspect of care. This proactive approach is supported by Lindley, Vasa, Sawyer, and Winter (1998), who indicated that most patients are willing to accept treatment despite limited benefits. Symptom control, emotional support and information were also reported by a minority of both groups as being what patients' perceive as being beneficial. Although healthcare professionals' main reason for pain management is often to enhance quality of life, effective symptom control can actually have more far reaching effects. According to Altilio (2006), it can also influence the grief and bereavement of surviving family members. Despite the majority of healthcare professionals indicating an inability to deal adequately with patients' emotions they did acknowledge emotional support as being an important aspect of care. Considering the long-term psychological distress associated with cancer the inclusion of psychosocial interventions would have to be considered a prerequisite for effective disease management (Rehse & Pukrop, 2002). In light of the previously mentioned difficulties associated with imparting information, as well as patients' inability to internalise and understand it, could lead one to question if the identified patients' need for information is for their benefit or for that of the healthcare professional. A study conducted by Heldal and Steinsbekk (2009), found that healthcare professionals communicate more easily with patients who are able to communicate using medical terminology. These patients' involvement are often seen as beneficial, while those who are unable to communicate biomedically and who are perceived as being uniformed are often dismissed from involvement in making treatment-related decisions. Would patients having more information thus be for their own benefit or would it simply make it easier for healthcare professionals to communicate with them? According to Say, Murtagh, and Thomson (2006), it should, however, be noted that just because most patients do indeed desire information and options does not mean that all of them have an interest in making treatment-related decisions.

A minority of the healthcare professionals in the private sector group indicated that what is perceived as being the most beneficial aspect of treatment is patient-specific. Viewing treatment needs as being individualised is in accordance with Arora et al. (2009), who indicated a need for personalised medicine to be practised within the context of patient-centered care. A minority of the healthcare professionals in the public sector indicated supportive social services as being what patients find most beneficial. Considering the fact that public sector patients are often plagued by poor socioeconomic circumstances and illiteracy, practical and social assistance are bound to be of value. According to Serin et al. (2004), there is a significant relationship between the systemic nature of medical issues and the social, material and psychological difficulties cancer patients experience. Having healthcare professionals to assist patients with the attainment of resources, by assisting with disability and childcare grant applications and food parcels, can thus have a positive impact on patients' adjustment and coping.

Multidimensional treatment of cancer requires continuous multi-professional collaboration in order to assess and address patients' individualised needs (Mathews et al. 2009). Achieving individualised patient-centered care also requires patient participation (Kvåle & Bondevik, 2008). Considering the complexity of the above-mentioned process and the lack of resources and other challenges, previously discussed, one can understand healthcare professionals' need for patients to have insight and understanding regarding the processes involved. Healthcare professionals from both sectors indicated a need for patients to understand and accept the following: they are doing their best, there are no guarantees, treatment is time-consuming, patients need to take responsibility for their own health, as well as for patients to internalise and apply the information provided. Healthcare professionals, in the private sector, also indicated a need for patients to appreciate the fact that they were unique individuals and that their treatment will be approached and experienced as such.

Both groups indicated a need for additional training pertaining to certain areas of oncology care. The fact that healthcare professionals in the private sector primarily indicated a need for continuous skills development focusing on keeping abreast of new developments in the field, while those in the public sector expressed a need for even basic oncology training, can possibly be related to the vast difference in resources at their disposal (Bateman, 2011). A minority of the healthcare professionals in the public sector reported being transferred to oncology despite having little or no oncology training. A possible explanation for this could be that their working conditions are not conducive to retaining competent well-trained staff, thus creating such a need for healthcare workers that even those lacking skills and knowledge of cancer as a speciality area of practice get assigned to the oncology department. Despite both sectors following a multi-professional team approach both groups still indicated a need to know more about what exactly each profession's role is and how it all fits together. This could help them move towards true multi-professional team collaboration as opposed to patients just being treated by multiple professionals at the same time. The indicated need for training regarding the psychological care of cancer patients is well documented around the world (McDonnell et al. 2002; Maguire & Pitceathly, 2003; Mohan et al. 2005; Kenny et al. 2007; Addington-Hall & O'Callaghan, 2009). The current study indicating healthcare professionals' inability to adequately deal with patients' emotions, coupled with their perceived need for psychological care training, indicate South African healthcare professionals as being no exception. This also confirms Pillay's (2001), observation that despite advocacy for the biopsychosocial model the implementation thereof has not yet been fully realised. One of the healthcare professionals in the public sector also indicated a need for training in financial management. Considering the increasing lack of resources, coupled with an increasing number of patients demanding care, creates an obvious need for finding alternative operational strategies. This is supported by Graham, Ramirez, Field, and Richards (2000), who indicate the inadequacy of services and concerns over future funding as being a source of stress for healthcare professionals.

Despite a minority of the healthcare professionals in both groups indicating there being no need for any changes in the current treatment process, the majority of them had numerous suggestions for improving care. Both groups reported a need for improved education and information regarding cancer and its treatment, believing that this could possibly lead to earlier detection and thus improved treatment outcomes. However, considering the multi-ethnic nature of South Africa and the fact that we have 11 official languages pose several challenges for the implementation of such a strategy. This is supported by Saleh et al. (2012), who indicated that when dealing with a multi-ethnic country, different ethnic groups may require different campaign approaches. More research is thus needed to determine the acceptability and effectiveness of different approaches if successful outcomes are to be obtained. Other changes indicated by both groups included more knowledge and collaboration regarding a multi-professional team approach, improved funding and the adequate distribution and monitoring thereof, as well as the provision of more social assistance to patients.

Additional changes indicated by the private sector included less interference from medical aids, treatment equality, an effective cancer registry and finding a cure. Treatment equality for all patients, regardless of socioeconomic status, would be the ideal. Unfortunately, it appears that the treatment gulf that exists between the private and public healthcare sectors can only be bridged by money (Bateman, 2011). Taking into account South Africa's level of poverty, unemployment, illiteracy and fraud it is highly likely that bridging this gap will forever remain a distant goal. Having an effective cancer registry will enable healthcare professionals to determine exactly what they are dealing with on a larger scale. Having reliable statistics regarding prevalence and mortality will help determine which areas of cancer treatment requires more research and could hence lead to improved treatment outcomes. According to Twycross (2002), medical care is a continuum, ranging from complete cure to symptom control and while there is a range of interventions to be conducted in between, for many doctors the concept of death remains something that needs to be defeated. The fact that finding a cure was identified as being a change needed in the treatment of cancer could, however, also be linked to the concept of hope, providing a sense of purpose and something to work towards.

Suggestions made by the public sector on how productivity and efficiency could be increased involved the improvement of human and technical resources. For this to be achieved there would need to be cooperation on government level. This involvement would, however, need to be more than the mere allocation of funds. Rigorous monitoring would be required to ensure that the funds are used appropriately.

Both groups also indicated a need for governmental involvement in cancer research. While the private sector indicated a need for research to focus on neglected areas, such as rural and underserviced areas, those in the public sector suggested research focus on prevention and early detection, as well as on the improvement and use of treatments currently available. This differentiation could possibly, once again be related to the differential resources at their disposal. While those in the private sector have access to the latest drugs, those in the public sector are stuck with the limited number making up the government funded formulary. Those in the private sector also indicated a need for research that produces serviceable recommendations that can be implemented in practice. This sentiment was shared by those in the public sector indicating a need to move towards evidence-based medicine. According to Sackett, Rosenberg, Gray, Haynes, and Richardson (1996), evidence-based practice involves integrating the best external evidence with clinical expertise and patients' choice.

## Conclusion and Recommendations

When considering the fact that the majority of the healthcare professionals, in both groups, indicated active medical treatment as being what patients perceive as being most beneficial, patients' emotions as being obstacles to providing care, as well as a perceived lack of training to provide adequate psychological care, could lead one to conclude that the biomedical model is indeed still alive and kicking. The multi-professional team approach followed also appears to be more of a 'being treated by multiple professionals at the same time' rather than a true collaboration among professionals working towards a common goal. The fact that the majority of the differing experiences, as reported by the private and public healthcare sectors, can be traced back to the differing resources at their disposal once again highlights the socioeconomic divide between these two sectors. It also indicates that the treatment deficiencies experienced in the public sector is often not related to healthcare professionals' inability to provide effective care, but rather to healthcare professionals not having access to the resources needed for sufficient care to be executed. If this discrepancy is to be addressed there would have to be cooperation on a government level, involving the allocation of funds, as well as rigorous monitoring ensuring that the funds made available are being used appropriately.

The following recommendations with regard to improving cancer treatment can be made:

- Government to allocate funds to the oncology departments in the public sector, as well as to monitor and ensure the effective use of such funds. Funds should be used to increase human and technical resources, as well as for staff development.
- More treatment sites need to be developed and existing sites need to be updated if we are expected to deal with the increase in patient numbers.
- Continuous research to be conducted focusing on refining treatment and finding a cure.
- Funds need to be allocated towards the development of an effective transport service to be used by patients.

- Development of effective interpreting services in an effort to address the difficulties encountered by a multilingual society. Interpreters, with the relevant knowledge pertaining to oncology treatment and the terminology used, need to be employed and be available on a continuous basis.
- Healthcare professionals need to commit to contributing towards keeping the cancer registry up to date.
- Cancer awareness campaigns, which are culturally sensitive, need to be developed and implemented.
- Healthcare professionals' communication skills need to be refined to include dealing with emotionally charged situations in an empathic and effective manner.
- Healthcare professionals to receive additional training regarding the psychosocial effects of cancer and how to deal with this aspect of patients' needs.
- Healthcare professionals need to be aware of the fact that cultural sensitivity requires more than the mere knowledge of different cultural beliefs. It requires an understanding that allows for the implementation of a treatment strategy that makes allowances and incorporates patients' beliefs into achievable treatment goals.
- Healthcare professionals need to commit to continuously developing their skills and keeping abreast of new developments in the field.
- More of an effort needs to be made towards the implementation of a holistic treatment approach, based on true collaboration and cooperation between the different professions involved in cancer care.

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## Addendum 1

Cancer Treatment Questionnaire

1) What has your experience working in the field of oncology been like?
2) Which aspects of treatment do you think patients perceive as being most beneficial?
3) a) What are the challenges/obstacles you experience when treating cancer patients?
   b) Which aspect of your work do you find most satisfying and why?
4) What are your views on the information provided to/and the communication opportunities with patients during the treatment process?
5) a) What do you think patients perceive as being their most prominent needs during the treatment process?
   b) What do you think patients want most from the professionals treating them?
6) The process of providing cancer treatment is often very complex and places various demands and expectations on professionals. Are there any area/s of treatment for which you feel you have received insufficient training?
7) If you had the power to change anything regarding the cancer treatment process what would it be and why?
8) What is the one thing you wish the patients you treat understood?
9) In your opinion, how can we improve cancer treatment in South Africa?
10) We are interested in any other comments you might have concerning your experiences working in the field of oncology. Please write in the space below anything you would like us to take note of:

## Table 1

Oncology Experiences: Identified Themes

| **Theme** | **Sub-theme** | **Private Healthcare** | **Public Healthcare** |
|---|---|---|---|
| **General experience of working in oncology** | Positive | ✓ | ✓ |
| | Emotionally challenging | ✓ | ✓ |
| | Opportunity for learning | ✓ | ✓ |
| | Personal growth | ✓ | ✓ |
| | Big responsibility | ✓ | ✓ |
| | Life’s calling | ✓ | |
| | Misconceptions | | ✓ |
| **Most satisfying aspects of working in oncology** | Being of service and making a difference | ✓ | ✓ |
| | Seeing improvement in patients | ✓ | ✓ |
| | Being appreciated | ✓ | ✓ |
| | Learning experience – intellectually challenging | ✓ | ✓ |
| | All aspects of working in oncology | | ✓ |
| **Challenges and obstacles** | Lack of resources | | ✓ |
| | Work overload due to patient numbers | ✓ | ✓ |
| | Patients’ lack of resources | ✓ | ✓ |
| | Patients’ cultural beliefs and lack of understanding | ✓ | ✓ |

|  |  |  |  |
|---|---|---|---|
|  | Patients’ emotions | ✓ | ✓ |
|  | Patients’ families | ✓ | ✓ |
|  | Complexity of oncology | ✓ | ✓ |
|  | Inevitability of death | ✓ | ✓ |
|  | Language barriers | ✓ | ✓ |
|  | Administrative duties | ✓ | ✓ |
|  | Medical aids | ✓ |  |
|  | Work politics |  | ✓ |
|  | Patients’ unhealthy lifestyle |  | ✓ |
| **Coping strategies** | Personal care | ✓ | ✓ |
|  | Counselling and debriefing | ✓ |  |
|  | More leave days | ✓ |  |
|  | Peer support |  | ✓ |
|  | Open minded and trust in self |  | ✓ |
| **Information and communication** | Sufficient | ✓ |  |
|  | Insufficient |  | ✓ |
|  | Obstacles |  |  |
|  | • Patient capabilities | ✓ | ✓ |
|  | • Time constraints | ✓ | ✓ |
|  | • Language barriers | ✓ | ✓ |
|  | • Cultural diversity | ✓ | ✓ |

| | | | |
|---|---|---|---|
| **Understanding of patients' perceptions and needs** | Patient perspective: most beneficial | | |
| | • Active treatment | ✓ | ✓ |
| | • Symptom control | ✓ | ✓ |
| | • Emotional support | ✓ | ✓ |
| | • Information | ✓ | ✓ |
| | • Patient specific | ✓ | |
| | • Social services | | ✓ |
| | Patient perspective: need from staff | | |
| | • Information | ✓ | ✓ |
| | • Empathy and understanding | ✓ | ✓ |
| | • Symptom control | ✓ | ✓ |
| | • Respect | ✓ | ✓ |
| | • Cure | ✓ | ✓ |
| | • Hope | ✓ | ✓ |
| | • Professionalism/competence | | ✓ |
| | • Social services | | ✓ |
| **Wanting patients to understand** | Do our best | ✓ | ✓ |
| | No guarantees | ✓ | ✓ |
| | Treatment – team effort/time consuming | ✓ | ✓ |
| | Need to take responsibility for own health | ✓ | ✓ |
| | Information provided | ✓ | ✓ |
| | Unique individual | ✓ | |

| | | | |
|---|---|---|---|
| **Insufficient training** | None | ✓ | ✓ |
| | Oncology | ✓ | ✓ |
| | Multi-professional team approach | ✓ | ✓ |
| | Psychological care | ✓ | ✓ |
| | Financial management | | ✓ |
| **Changes needed within the healthcare system** | None | ✓ | ✓ |
| | Education and information | ✓ | ✓ |
| | Multi-professional team cooperation | ✓ | ✓ |
| | Funding | ✓ | ✓ |
| | Patient assistance | ✓ | ✓ |
| | Medical aid interference | ✓ | |
| | Treatment equality | ✓ | |
| | Cancer registry | ✓ | |
| | Finding a cure | ✓ | |
| | Increased productivity/efficiency<br>• More staff<br>• Staff competence<br>• Protocols/systems<br>• Updating resources<br>• More treatment sites | | ✓ |
| **Research** | More research needed | ✓ | ✓ |

# Chapter 5: Conclusions, Limitations and Recommendations

## Conclusions

The general aim of the study was to explore patients' and healthcare professionals' perceptions and experiences of cancer treatment in the private and public healthcare sectors in the Eastern Cape, South Africa. Identifying similarities and discrepancies, stemming from their differing viewpoints, provides information for the development of treatment policies and educates professionals on how best to meet patients' needs. Healthcare professionals need to do more than provide what is 'objectively' or 'scientifically' considered high quality care. Even the best treatment in the world will not be perceived as such if it does not fit with the patient's view of his/her illness (Nauert, 2012). Understanding and incorporating patients' illness perceptions into healthcare is thus crucial if treatment outcomes are to be improved (Petrie & Weinman, 2012).

Findings indicate that the majority of the healthcare professionals in the current study are still primarily following a biomedical approach. A need to move towards a biopsychosocial approach, with true collaboration among multi-professional team members were, however, indicated by healthcare professionals and patients alike. Difficulties and frustrations experienced during the treatment process can be attributed to being either resource-related or the result of the composition of the South African population's characteristics. The majority of the differences experienced by both the patients and the healthcare professionals within the private and public healthcare sectors can be traced back to the differing resources at their disposal. Difficulties that were not necessarily directly related to the availability of healthcare resources included the multi-ethnic nature of South Africa, which results in differing cultural beliefs and language barriers, as well as illiteracy and unemployment. These findings indicate that the majority of the difficulties experienced could be seen as being contextual problems rather than being directly related to cancer treatment per se. This is consistent with Serin et al. (2004), who indicated that there is a significant relationship between the systemic nature of medical issues and the social, material and psychological difficulties cancer patients' experience. The systemic nature of the healthcare needs identified in the current study thus reinforces the necessity for healthcare in South Africa to move towards a more biopsychosocial model with true collaboration between healthcare professionals working towards a common goal. Unfortunately, it is the same lack of resources, time constraints and high patient numbers creating the current difficulties, which also inhibits the incorporation of psychosocial aspects of care.

Lack of resources are, however, not the only factor sustaining the biomedical approach to cancer care. According to Twycross (2002), it is often a conscious or subconscious mindset. For many doctors the concept of death remains something that needs to be defeated. Even in the face of objective assessments where cure is considered an unrealistic outcome, some doctors still find it difficult to recognise and accept the approach of inevitable death. Most patients also want to believe that death can be kept at bay indefinitely and thus encourage doctors to treat, upholding their unrealism (Twycross, 2002). Cancer and its treatment are associated with a large number of symptoms (Bennion & Molassiotis, 2013). For many patients the management of cancer is thus a fulltime job, and as much as psychosocial interventions might be helpful, they are not prioritized by most patients as being vitally important (Hendrick, 2013).

This penchant for biomedical treatment is consistent with findings in the current study. The majority of the patients in both sectors indicated actively receiving treatment as making them feel proactive and providing hope. This is consistent with healthcare professionals' perceptions of patient preferences as actively receiving treatment were identified by healthcare professionals as being the aspect of care patients perceive as being most beneficial. Actively receiving or administering treatment provides a semblance of control over the disease process (De Haes & Koedoot, 2003), which allows for the maintenance of hope (Truant & Bottorff, 1999).

In the current study the need to move towards a biopsychosocial approach, with true collaboration among multi-professional team members, were indicated by healthcare professionals representing the private and public sectors. Although patients in the current study did not specifically identify the need for more psychosocial interventions they did indicate having various experiences for which this aspect of care would be beneficial. Comments made in this regard included the acknowledgement that psychosocial aspects of treatment can sometimes be more overwhelming than the actual treatment, as well as the fact that acceptance, placing things in perspective and cultivating a positive mindset are important aspects in coping with cancer and the treatment thereof. References were also made to the emotional pain cancer patients have to go through, that treatment often has far-reaching effects on all aspects of patients' lives, as well as the need to receive more empathy from healthcare professionals. The onus is thus on the healthcare professionals to suggest and encourage patients to access psychosocial interventions during cancer treatment.

The majority of the differences and frustrations experienced by both the patients and the healthcare professionals within the private and public healthcare sectors can be traced back to the differing resources at their disposal. According to Bateman (2011), the screening and treatment access gulf between the private and public healthcare sectors can clearly be seen in their hugely differing treatment routes and outcomes. While private sector patients have access to information, social workers and support groups, those in the public sector face life-threatening waiting times and a lack of empathy by public sector staff weighed down by patient numbers and a lack of resources (Pillay, 2002; Bateman, 2011). The current study, however, also highlighted the fact that treatment deficiencies experienced in the public sector are often not directly related to healthcare professionals' inability to provide effective care, but rather to healthcare professionals not having access to the resources needed for sufficient care to be executed. In spite of this the resulting effect remains the same. The systemic problems in the public sector due to lack of technical and human resources negatively impact patients' treatment experiences.

Findings in the current study also indicated that although the majority of the difficulties experienced, by both the patients and healthcare professionals are not directly related to cancer care per se, they do have a negative impact on treatment experiences. The multi-ethnic nature of South Africa is generally viewed as being rewarding, as exposure to diversity is often seen as being an enriching experience. In the current study it was however highlighted that in relation to healthcare, differing cultural beliefs and language barriers can negatively affect cancer treatment. Considering the multi-ethnic nature of South Africa (Ribot, Morris, Sealy, & Maggs, 2010), there is an increased likelihood of treatment situations where the healthcare professionals and patients stem from different cultural backgrounds, influencing their healthcare beliefs and behaviours (Pfaff & Couper, 2009). Although English is commonly used across South Africa, it is only the fifth most-spoken home language (South Africa Fast Facts, 2007). Communicating detailed information about diagnoses and treatment regimes, while facing not only a language barrier but also differing cultural beliefs, influencing health perceptions and symptom experiences, can be challenging. Considering the lack of basic resources, especially in the public healthcare sector (Bateman, 2011), the employment of qualified interpreters are likely to be considered a luxury that they can ill afford. Patients in the current study indicated a preference for being treated by healthcare professionals belonging to the same culture as them as a way to bridge the communication gap. The implementation of such a strategy may prove challenging in post-apartheid South Africa as it might remind people of past segregation laws. Patients' poor socioeconomic circumstances, illiteracy and unemployment, were also indicated as having an adverse effect on cancer treatment. These factors often lead to transport problems, defaulting treatment, poor nutrition, unhealthy lifestyle choices, and difficulty in understanding the necessary information regarding cancer and its treatment needed if patients are expected to make informed decisions regarding their care. It is thus imperative for healthcare professionals to be aware of the importance of adopting a systemic approach if effective cancer treatment is to be provided (Serin et al. 2004). Patients' context of life circumstances thus need to be taken into consideration when developing treatment plans and awareness campaigns. Multi-dimensional treatment with continuous multi-professional collaboration is thus needed if patients' individualised needs are to be addressed (Mathews, West, & Buehler, 2009).

According to Kvåle and Bondevik (2008), achieving individualised patient-centered care requires patient participation. While patients in the current study indicated a need for healthcare professionals to place more emphasis on patient experiences, healthcare professionals also expressed a desire for patients to take more responsibility for their own health. This is consistent with Carlsson, Segesten, Nilbert, and Nilsson (2007), who acknowledge the importance of balancing experiential and professional knowledge when treating cancer patients. It should, however, be acknowledged that an appropriate level of patient participation is also very patient-specific. In the current study, patients from both sectors expressed being comfortable with leaving the final decision-making regarding treatment to the healthcare professionals. The extent to which they wished to be consulted, however, differed significantly from patient to patient regardless of where treatment was being received. This is supported by Say, Murtagh, and Thomson (2006), who reported that despite the majority of cancer patients preferring to be informed about different options during the decision-making process, interest in actually making treatment decisions can vary considerably. In the current study, a minority of the healthcare professionals in the private sector acknowledged this by indicating patients' treatment needs as being patient-specific and indicating a need for personalised medicine to be practised within the context of patient-centred care (Arora, Street, Epstein, & Butow, 2009). It should, however, be acknowledged that in a developing country such as South Africa, plagued by competing healthcare priorities (Michelow, McKee, & Hlongwane, 2006), poor resources (Pillay, 2002), cultural diversity (Wright, 1997), language barriers (Mullin et al. 2000), unemployment, illiteracy (Statistics South Africa, 2003) and the differential standards of treatment found in the private and public healthcare sectors (Bateman, 2011), the implementation of such a strategy is no easy feat.

In the current study, healthcare professionals' approach to treatment is very different from what patients identified as being the ideal. Healthcare professionals' perceptions of what patients ideally expect from them, are not concordant with patients' own perceptions. Patients indicated a preference for healthcare professionals who take a more emotional and supportive approach to treatment, exhibiting characteristics such as friendliness, patience, and a sense of humour. Healthcare professionals, however, perceived patients as preferring a more ‘professional’ and practical approach, focusing on providing information, symptom control, cure, and providing professional and competent services. Although these aspects of care were indeed indicated by patients as being of value it is the way in which healthcare professionals go about delivering these aspects of care that need to be revised. According to Hendrick (2013), the academic discipline or medical profession to which the healthcare professional belongs is less important than the life experience and skills set they possess. In the present study, healthcare professionals’ failure to identify the above-mentioned patient needs could be related to them being uncomfortable with patients’ emotions and their perceived lack of training in providing psychological care. It is, therefore, imperative for healthcare professionals to receive additional training regarding the psychosocial effects of cancer and how to deal with this aspect of care effectively.

The importance of biomedical care in cancer treatment is not disputed; cancer does after all originate as a physical disease. In light of the obstacles identified in the current study the importance of taking a holistic approach to treatment is, however, reinforced, as there is little doubt that psychosocial support forms an essential part of cancer treatment (Miller, Pittman, & Strong, 2003).

## Limitations

While this study was limited by the fact that it was conducted in only one government-funded hospital and one private treatment facility in the Eastern Cape, South Africa, with a relatively small number of participants, its aim was not to generalise but rather to provide a vivid representation of the perceptions and experiences of patients and healthcare professionals with regard to cancer treatment in a South African context.

The healthcare professionals who participated in this study were from different professions, had different levels of education and vastly different years of experience working in oncology. The fact that the majority of the participants were represented by the medical profession (oncologists, medical officers, radiation therapists, nurses) could explain the identified need for additional training in providing psychosocial care. It is, however, felt that this is a true reflection of the oncology environment as medical staff providing patient care is far more numerous than the allied healthcare professionals working in this field.

Although conducting individual interviews during the third sub-study was deemed impractical, due to participants’ workload, and unnecessary for data saturation to be reached it should, however, be noted that the inclusion of such a measure might have provided alternative information not captured in the current study. The use of interpreters, to translate when language barriers were experienced, can potentially be seen as a limitation of the study. According to Squires (2009), the process of translation often results in changes to language as it is not only the literal meaning of the word that gets translated, but also how the word relates conceptually in the context. In the field of healthcare a word or phrase to describe a particular disease or treatment concept might not even exist in the participant's first language (Fredrickson, Rivas Acuña, Whetsell, & Tallier, 2005). The fact that registered healthcare professionals (social worker, professional nurse) provided the interpretations are believed to minimise the above-mentioned problems as they are not only familiar with the participants' first language but also with the medical terminology used. It is, however, acknowledged that data collected in this manner is not the ideal as various inaccuracies, of which the researcher might be unaware, could potentially occur.

The fact that cancer is such a common disease and affects so many people, on either a personal level or through family and friends, could potentially influence one's outlook and attitude. In an attempt to minimise possible bias, there was continuous corroboration between the researcher (first author) and the promoters (second and third authors) during every phase of the study.

## Recommendations

Overall, the findings in the current study indicate the importance of acknowledging patients' and healthcare professionals' subjective perceptions of cancer treatment. Given the socioeconomic divide and the differential access to healthcare resources between the private and public healthcare sectors in South Africa, credence must be given to the allocation of resources in the public sector to ensure that all South African citizens have access to equitable healthcare. If this discrepancy is to be addressed there would have to be cooperation on government level, involving the allocation of funds, as well as rigorous monitoring to ensure that the funds allocated are being used appropriately. Funds should be used to increase human and technical resources, as well as for staff development. In addition to providing equitable care to all cancer patients, regardless of their socioeconomic status, the following recommendations on how to improve overall cancer care, in both sectors, can also be made:

- More treatment sites need to be developed and existing sites need to be updated if we are expected to deal with the increase in patient numbers.

- Continuous research should be conducted focusing on refining treatment and finding a cure.
- Funds need to be allocated towards the development of an effective transport service to be used by patients.
- Development of effective translation services in an effort to address the difficulties encountered due to South Africa's multi-lingual society. Interpreters, with the relevant knowledge pertaining to oncology treatment and the terminology used, need to be employed and be available on a continuous basis.
- Cancer awareness campaigns, which are culturally sensitive, need to be developed and implemented.
- Healthcare professionals' communication skills need to be refined to include dealing with emotionally charged situations in an empathic and effective manner, as well as how to tailor information to patients' individual needs.
- Healthcare professionals need to be aware of the fact that cultural sensitivity requires more than the mere knowledge of different cultural beliefs. It requires an understanding that allows for the implementation of a treatment strategy that makes allowances and incorporates patients' beliefs into achievable treatment goals.
- More of an effort needs to be made towards the implementation of a holistic treatment approach, based on true collaboration and cooperation between the different professions involved in cancer care.
- All healthcare professions should be encouraged to establish rapport and maintain a continuous supportive professional relationship with patients. This aspect of care should not be categorised as only being expected of social workers and psychologists.
- Healthcare professionals should provide guidance, while encouraging patient participation. Ultimately, the patient should be allowed to determine the level of involvement he/she is most comfortable with.
- Healthcare professionals need to acknowledge the importance of taking care of their own psychological health and should be encouraged to participate in supervision and regular debriefing sessions.

In South Africa all registered healthcare professionals are bound by regulation defining the acts, which are deemed to be appropriate as pertaining to his/her profession (Health Professions Act, 1974). Psychologists, for example, are only allowed to operate within the scope of practice of the category for which he/she is registered with the Health

Professions Council of South Africa and are, therefore, not permitted to provide patients with, or give advice on medical procedures or prescriptions. Psychologists are thus not permitted to provide medical care. Yet, findings in the current study, as well as other studies conducted all over the world indicate a desire for medical professions to provide psychosocial care. This leads one to question whether this can be considered as being a fair expectation, for we are basically expecting everyone involved in cancer treatment to be what Kenny, Endacott, Botti, and Watts (2000), refer to as being “multi-skilled generalists”. Would a more realistic and implementable approach thus not be to rather focus on refining collaboration and cooperation between different professions working towards the same goal with each providing care that is within his/her realm of expertise? Would the lack of resources in South Africa allow for such an approach, or is the “multi-skilled generalist” approach our only viable, if not ideal, option? It is suggested that more research be conducted on this matter.

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