

# An Investigation into the Quality of Life of Cancer Patients in South Africa

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## ABSTRACT

**Objective:** Cancer patients in Africa face unique challenges such as poverty, access to health care and under-resourced health-care systems. Although quality of life (QoL) of cancer patients has been well researched, the perspectives of cancer patients living in Africa are unknown. The objective was to explore what constitutes QoL for cancer patients accessing public health care in South Africa. **Methods:** A qualitative exploratory design was used, and data were gathered by means of in-depth interviews. Purposive sampling selected the participants, and the sample size was determined by saturation ( $n = 22$ ). The data were analyzed using Patton's method of content analysis. **Results:** The participants were aged between 20 and 79 years, with an average of 50 years. Most were female and represented seven cultural groups. Four themes that influence QoL arose from

the data: psychosocial-, physical-, spiritual and financial factors. **Conclusions:** QoL remains a complex phenomenon, enhanced and diminished by various individual factors. Poverty was a major issue and influenced the physical aspects of QoL, as the participants had to be strong enough to work and earn a living. Support from family, friends, and church members enhanced QoL, as well as religion and religious practices. Measuring QoL would be the next step to enable nurses to implement measures to improve QoL. Whether existing QoL instruments would be suitable for this patient population is not known and should be investigated before implementation.

**Key words:** Cancer, patient perspective, quality of life, South African cancer patients

## Introduction

Little is known about the quality of life (QoL) of cancer patients living in South Africa. Although QoL of cancer patients has been well researched, the perspectives of cancer patients living in Africa, who face unique challenges

such as poverty, access to health care and under-resourced health-care systems are unknown.<sup>[1-3]</sup> This study aimed to explore what constitutes QoL for cancer patients accessing public health care in South Africa. The public health-care

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sector provides care to more than 80% of the population who do not have medical insurance.

Irrespective of whether the treatment goal is cure, control of disease, or palliation, cancer patients need support through the cancer experience to ensure the best QoL possible for them and their families. QoL is a multifaceted phenomenon<sup>[4]</sup> and is defined in various ways. For instance, Mitchell<sup>[5]</sup> defines QoL as the difference between the hopes and expectations of an individual and what the person is experiencing at present, whereas Theofilou<sup>[6]</sup> defines it as an individual's satisfaction in view of the domains of QoL, which the individual considers as important.

Authors differ in describing the domains of QoL. The Ferrans and Grant model for QoL<sup>[7]</sup> includes four domains in QoL: health and physical functioning-, social and economic-, psychological/spiritual-, and family domains. Fitzsimmons and Middleton<sup>[8]</sup> include physical functioning-, psychological/emotional-, cognitive-, social-, and occupational domains, satisfaction with care, and global assessments in QoL, while the World Health Organization<sup>[9]</sup> measures QoL in terms of physical health, psychosocial and social relations, and the environment.

Various factors influence QoL including value systems, personal goals, and expectations, which reflect a person's evaluation of extrinsic and intrinsic circumstances.<sup>[4]</sup> Considering these factors, the QoL experience would depend on the perspective of the individual and not that of health-care providers.<sup>[10]</sup> The research problem for the study focused on the QoL of cancer patients in South Africa, specifically what contributes to and distracts from their QoL.

## Methods

We used an exploratory qualitative design. Qualitative research methods are used to investigate what people do, know, think, and feel,<sup>[11,12]</sup> and exploratory research is conducted when no other studies have been done in the area of interest.<sup>[13]</sup>

The setting, an academic hospital in the Gauteng Province of South Africa, which forms part of the public healthcare system, serves as a referral hospital for a number of hospitals in its referral chain and admits patients from other provinces and African countries. Cancer patients have access to surgery, radiotherapy, and chemotherapy.<sup>[14]</sup> The Department of Radiation Oncology treats more than 3500 cancer patients per year.<sup>[15]</sup>

The target population was all cancer patients accessing public health services for treatment. The accessible population<sup>[16]</sup> was cancer patients receiving treatment at the chosen health-care facility. The inclusion criteria were 18 years and older, receiving chemotherapy, radiotherapy,

or a combination at the hospital of choice and willing to participate.

Purposive sampling was used to select the participants.<sup>[16]</sup> A sampling grid guided the sampling to include participants who received treatment for different types of cancer, represented different cultural groups in South Africa, and were of both genders.

In-depth interviews to gather data were conducted<sup>[17]</sup> during February and March 2013. Two questions were posed: What makes life good? and What makes life hard? Probing and prompting questions were used to follow up on interesting topics, to clarify concepts and encourage participants to expand on their experiences.<sup>[12,18]</sup> Demographic data were gathered by means of a preinterview questionnaire.

After obtaining ethical clearance and approval from the hospital, patients attending the clinics at the Department of Radiation Oncology were invited to participate in the study. Twenty-four participants were recruited and two refused. The first author, an experienced oncology nurse, conducted the interviews in English. A registered nurse, conversant in English, and indigenous languages assisted with the language issues. Before conducting an interview, the researcher introduced herself and allowed time for the participant to introduce him/herself to establish a trusting relationship. The interviews were conducted in a private room to ensure confidentiality and on average, lasted an hour. The study was explained to the participants, and written informed consent was obtained. No harm was intended, and participation was voluntary.

The first interview pretested the questions, and as no difficulties in understanding were experienced, no changes were necessary. The interviews were recorded and field notes were taken. Each interview was transcribed verbatim and pseudonyms were chosen by the participants. Only one participant who was Zulu speaking could not converse in English and his son interpreted during the interview. The data were analyzed using Patton's<sup>[11]</sup> method of content analysis. During the analysis, the researcher read the transcriptions and field notes and made comments in the margin about concepts that emerged. After a second reading, the comments were organized into topics. The data were coded in a systematic way, which involved several readings. Topics that fit together were sorted into themes and categories, until no new categories emerged and all sources of data had been exhausted.

Data analysis was done concurrently with data gathering, to determine when data saturation occurred. Saturation was achieved after twenty interviews, and two more interviews were conducted to confirm no new information emerged. All three authors analyzed the data,

and a consensus meeting confirmed the emerging themes and categories.

Trustworthiness confirmed the rigor of the study, and the guidelines described by Shenton<sup>[19,20]</sup> were applied to enhance the rigor. Credibility was enhanced by means of well-established research methods and prolonged engagement in the field, which fostered a trusting relationship. Data source triangulation was achieved as patients with a wide range of cancers participated in the study. Honesty was enhanced by voluntary participation and the use of pseudonyms. Asking participants to choose their own pseudonyms allowed them to talk freely about their experiences. Credibility and dependability were enhanced by a thorough description of the setting and research processes.<sup>[13]</sup> Frequent discussions between the investigators further enhanced credibility by identifying errors and biases, and peer review was obtained by means of feedback after presentation of the proposal. Confirmability was achieved by means of an audit trail and data triangulation.<sup>[19]</sup>

## Results

### The participants

The participants were 22 cancer patients aged between 20 and 79 years, with the average age 50 years. Most were female (14 of 22) and Black (18 of 22); seven different cultural groups were represented [Table 1]. Four themes, psychosocial issues influencing QoL, physical aspects of QoL, spiritual factors influencing QoL, and financial factors that influence QoL, arose from the data.

### Psychosocial issues influencing quality of life

Having to live with cancer was not easy and words such as “horrible” and “my life is a mess” were used to describe what it was like to be diagnosed with cancer. Participants feared their diagnosis, the treatment, dying, and what would happen to their children after their death. Doctor explained: “Now I was in the machine, I don’t know what it look like that machine, it was my first time to go there... I was scared, because the people they said: ‘Hey, you’re going to burn.’”

Being supported by a spouse, family, friends, and church members enhanced QoL, as the participants could share their experiences. In contrast, being separated from their family during treatment caused emotional distress as the participants were worried about their treatment as well as who would care for their children at home. Thabo explained: “I left my daughter there at home... Now I worry about the treatment, I worry about my daughter and her child... what are they going to eat?”

Cancer also caused role changes and deprived participants from being breadwinners. Some were forced to use the social support grants allocated to their children for basic needs or had to ask family members for financial support.

Table 1: Demographic information of the participants (n = 22)

	n (%)
Age (years)	
20-29	2 (9.1)
30-39	3 (13.6)
40-49	6 (27.3)
50-59	4 (18.2)
60-69	5 (22.7)
70-79	2 (9.1)
Gender	
Male	7 (31.8)
Female	15 (68.2)
Culture	
Caucasian	3 (13.6)
Colored	1 (4.5)
Malayan	1 (4.5)
Xhosa	3 (13.6)
Tswana	2 (9.1)
Northern Sotho (Sepedi)	1 (4.5)
Southern Sotho (Sesotho)	3 (13.6)
Zulu	6 (27.3)
Tsonga	1 (4.5)
Congolese	1 (4.5)
Highest level of education	
No formal education	2 (9.1)
Primary school (Grade 1-7)	2 (9.1)
Secondary school (Grade 8-12)	15 (68.2)
Tertiary	3 (13.6)
Marital status	
Married customary	10 (45.5)
Married culturally	1 (4.5)
Single	7 (31.8)
Divorced	1 (4.5)
Widowed	1 (4.5)
Separated	0
Living with a partner	2 (9.1)
Reported cancer diagnosis	
Kaposi's sarcoma	3 (13.6)
Skin cancer	1 (4.5)
Ovarian cancer	1 (4.5)
Breast cancer	4 (18.2)
Head and neck cancer	1 (4.5)
Prostate cancer	4 (18.2)
Cervical cancer	7 (31.8)
Rectal cancer	1 (4.5)
Duration of illness	
0-6 months	2 (9.1)
7-12 months	9 (40.9)
13-24 months	9 (40.9)
2 years	2 (9.1)
Treatment received	
Chemotherapy	1 (4.5)
Radiotherapy	12 (54.5)
Chemoradiation	8 (36.4)
Chemoradiation-surgery	1 (4.5)
Place of residence	
Rural	11 (50.0)

*Contd...*

Table 1: Contd...

	<i>n</i> (%)
Urban	11 (50.0)
Employment	
Unemployed	8 (36.4)
Pensioner	6 (27.3)
Domestic work	2 (9.1)
Homemaker	1 (4.5)
Self-employed	4 (18.2)
Teacher	1 (4.5)

Participants were confronted with body image changes and the sexual complications of cancer, which had a negative influence on their QoL. Pieter said, "Before I got cancer, we could do something, but now we can't (have sex)... I told the doctor 'You are busy making a woman out of me'."

### Physical aspects of quality of life

Being physically strong enough to work, carry out normal household tasks, and take care of themselves enhanced QoL. Being able to work allowed participants to earn an income and keep busy. Thabo said: "I enjoy cleaning my house, doing my own washing with my own hands... since this cancer I am going to enjoy things more... To do things for yourself is better than to lie there..."

In contrast, the physical sequelae of cancer and its treatment had a negative influence on QoL. Fatigue made it hard to do household tasks and to engage in paid work, while weight loss led to a poor body image and suggested to participants that they would not get better and were going to die. Busie said, "I feel bad. It's not nice... now I'm hiding myself... I'm not going around, because people say 'oh, Busie, you're so slim,' you know. So I don't want this shame, shame thing... It's like I'm going to die, you see... It's like... I won't get better..."

Pain had a negative influence on the QoL of the participants, and good symptom control was important. Steve said, "If you haven't got pains that day, it's a big happy day..." In addition, symptoms such as anorexia, nausea and vomiting, diarrhea, and stomach cramps also had a negative influence on QoL. Poppy said, "I lost weight, vomited, loss of appetite... that's how it affected me... and diarrhea also... It was not easy, but... I thought I was strong... but it was not easy, not easy at all..."

### Spiritual factors influencing quality of life

Spirituality played an important role in the participants' lives and in their QoL. Believing in God resulted in feeling safe and protected and gave participants the opportunity and courage to continue and get their lives in order. Prayer and being able to go to church was important to many as it meant being accepted and being accepted reduced their

stress levels. Having cancer led to spiritual growth and a closer relationship with God for most. Petrus explained, "... so I just pray, I give everything to God... it's up to You what's happening to me. I ask Him to protect me." All participants were Christians, except one participant who was a Muslim woman.

Conversely, some participants had problems with their spiritual lives and having cancer and being treated hindered them from praying and taking part in religious practices. Busie explained, "The problem is when I'm praying... maybe I'll only say two or three words, then I'll cut... I don't know why."

Hope played an important role in participants' QoL. Having faith gave hope and the courage to go on with their lives and gave peace among the turmoil of cancer. Steve explained: "At present it's a bit special thing, because I'm a Christian. Then I'm hoping to get the better life in future, because now we can struggle there and there, but in future I'm hoping to get the better life. Even if I die now, the resurrection is there, and then that's my hope, that's what makes me happy, even if I'm sick. It gives me peace."

### Financial factors that influence quality of life

Financial problems had the greatest influence on QoL and added to participants' burden. Most of the participants struggled to survive without an income, living only on old age pensions and support grants. Some became financially dependent on family members, which was hard for them. Many were unable to afford nutritional food. Sandy described, "... I'm used to being independent, and I don't like to stand with my hand the whole time... When I, on the spur of the moment, want to eat a chocolate, I don't want to say 'Hey, please give me ten rand, I want to buy a chocolate'... you know what I mean..."

Having a regular income enhanced the QoL of the participants; some were employed, while others had a business or received financial support from children and family members. A regular income not only allowed participants to care for their daily needs but also gave them a sense of self-worth. Nicole said, "My work makes me feel good, the people I'm working for... I started sewing and I'm selling all that. Just makes me feel good to look at what I'm doing with my own hands... just comes perfect and I sell to people. That's self-support. I'm not short of money, because of all that."

## Discussion

The study provided evidence of several factors contributing to and decreasing QoL. Poverty had the greatest influence on QoL and influenced the physical aspect, as participants had to be strong enough to work and

earn a living. This finding is supported by Kimman *et al.*<sup>[21]</sup> who state that cancer can be a major cause of poverty, either due to the cost of treatment or the influence it has on the ability of people to work. Finding that poverty was an important factor decreasing the QoL of the participants in our study came as no surprise, as 26.5% of the South African population are unemployed<sup>[22]</sup> and 53.8% live in poverty, of whom 21.7% live in extreme poverty.<sup>[23]</sup> Gany *et al.*,<sup>[24]</sup> in a USA study, found food insecurity decreases QoL and has a negative influence on functional, physical, social, and emotional well-being in cancer patients. In addition, the conceptual models for QoL of Ferrans and Hacker<sup>[25]</sup> confirm that employment status, the ability to take care of financial needs, and financial burden are important aspects of QoL.

Support from a spouse, family, friends, and church members enhanced QoL, whereas separation from the support system had a negative influence. African culture supports the philosophy of Ubuntu, which is based on the precept that “a person is a person through other people”<sup>[26]</sup> and enunciates how people and communities should interact.<sup>[27]</sup> Ubuntu includes interdependence in terms of sharing and caring<sup>[28]</sup> and probably explains the negative influence separation from family members had on the QoL of some participants. However, social support is also important in other cultures. A study conducted in Turkey<sup>[29]</sup> found that cancer patients who experienced high levels of social support were not hopeless or lonely, while Applebaum *et al.*,<sup>[30]</sup> in a USA study, found a significant association between higher levels of perceived social support and QoL.

Weight loss and sexual dysfunction had a detrimental influence on QoL. In some African cultures, being overweight is associated with dignity, respect, wealth, and strength and overweight women are considered healthy and beautiful. Being thin is considered a sign of unhappiness and suffering from HIV and AIDS and tuberculosis,<sup>[31-33]</sup> which are associated with stigma.<sup>[34]</sup> Gilbert *et al.*,<sup>[35]</sup> in a study focusing on sexuality in cancer patients, reminds us that changes in sexuality can be one of the most difficult aspects of life after a cancer diagnosis and as seen in this study, can have a detrimental influence on QoL.

Spirituality and being able to engage in religious practices enhanced QoL, in contrast to the inability to participate or pray. This finding is supported by Paiva *et al.*,<sup>[36]</sup> who, in a study focusing on the impact of religion and individual prayer activities in people living with advanced cancer, found individual prayer activity and global religious scores had a positive influence on QoL. In addition, Buckley<sup>[37]</sup> states that faith in a spiritual world, religion, and religious practices foster hope, which is confirmed by our study

and supported by Olsman,<sup>[38]</sup> who related psychospiritual well-being to hope.

## Limitations

No qualitative study reflects the only true meaning, as the narratives could be interpreted in various ways. However, we believe the themes emerging from the data are authentic and applicable to others receiving cancer treatment in Africa, as there are overlapping issues, which might apply to all these patients.

## Conclusion

QoL remains a complex phenomenon and is enhanced and diminished by various individual factors. Poverty was a major issue and influenced the physical aspects of QoL, as the participants had to be strong enough to work and earn a living. Support from family, friends, and church members enhanced QoL, as well as religion and religious practices. Measuring QoL would be the next step to enable nurses to implement measures to improve QoL. Whether existing QoL instruments would be suitable for this patient population is unknown and requires investigation before implementation.

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## Conflicts of interest

There are no conflicts of interest.

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