

## Experiencing Uncertainty: Lived Experience of Having Cancer among Patients in Vhembe District of Limpopo, South Africa

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**KEYWORDS** Cancer Patients. Cancer Diagnosis. Experiences. Uncertainty

**ABSTRACT** The purpose of this study was to explore and describe the experiences of patients diagnosed with cancer in Vhembe district, Limpopo Province. A qualitative, exploratory, descriptive and phenomenological design was used. A purposive theoretical sample of patients who were diagnosed with different cancers within 2-5 years in a regional hospital in Vhembe district of Limpopo Province was obtained. Data was collected through in-depth interviews with participants who were in remission phase or undergoing treatment and. data saturation occurred after in-depth interviews with eight participants. Field notes were also used during data collection to capture non-verbal communication from participants. The findings revealed that cancer patients experienced a sense of uncertainty, withdrawal and isolation, lack of proper communication and attitudes and adjusting to the existential body changes. Recommendations that are described focused on understanding what it is like to have cancer and filling the gaps of patient's expectations and addressing emotional and physical needs.

### INTRODUCTION

Cancer is a major health threat to morbidity and mortality rate in the world. Every year cancer rates increase by 2 percent and every year cancer is responsible for the death of nearly 5 million people worldwide (Oskel et al. 2010). Breast cancer in females and lung cancer in males are the most frequently diagnosed and the leading cause of death for each sex in both economically and developed countries. Prostate cancer is the most frequent cancer among males, with cervical cancer being the third commonly diagnosed and the fourth leading cause of death worldwide (Jemal et al. 2011).

Cancer is a serious disease as it affects not only the individual who gets sick, but also all family members, it is perceived by patients as life threatening illness, contributing to emotional and psychological suffering. Most patients describe it as death, pain or disorder and some patients experience conflict and disharmony between their positive belief system and the reality of their current situation (Oskel et al. 2010; Chio et al. 2007).

As a developing country, South Africa is experiencing an increase in life expectancy, and as people live longer they are bound to develop more lifestyle-related diseases, including cancer. According to the World Health Organization's (WHO 2012) latest statistics, 8.2 million people died of cancer in 2012. About 47,000 of these deaths occurred in South Africa where

cancers of the lung, esophagus, breast and prostate are among those most common forms of cancer. One in every 38 women in South Africa will develop cervical cancer, and although it is the second commonest cancer, it kills more women than breast cancer, which is the most common type of cancer among South African women. Government's latest and boldest step to fight cancer is the roll out of the vaccine for the Human Papillomavirus (HPV), which is responsible for most cervical cancer cases. Starting in the year 2014, all girls between the ages of nine and 11 in public sector schools will be vaccinated (Stassen 2014).

Receiving a cancer diagnosis and undergoing treatment, can cause anxiety and compromise satisfaction and self-esteem. Quality of life diminishes very quickly when one is fearful, fatigued, in pain, enduring therapeutic side effects, or contemplating the possibility of treatment failure and death. Therefore the study sought to explore and describe the experiences of patients diagnosed with cancer.

### METHODOLOGY

#### Research Approach

Phenomenological, qualitative research approach was used in order to explore the experiences of cancer patients within the context of their daily lives. Phenomenology is the thorough, systematic study of human experience that

aims to produce insightful descriptions of the way people experience their world (Creswell 2009).

The semi-structured interview technique used in this study was guided by van Manen's (1999) approach, as a way to gain access to the lived experience of patients suffering from cancer. The interview method provided a means for exploring and gathering experiential narrative material that served as a resource to derive meaning of the lived experience.

Purposive and theoretical sampling method was used to select participants who were above 20yrs and experienced the diagnosis of cancer, and were receiving treatment on outpatient basis. Five women and three men participated in the study, and represented various background and socio-economic standing. The participants were treated for various types of cancer, such as breast, cervical, skin, stomach and bladder.

Data were collected through in-depth interviews which lasted for, an hour to one and half hours. Interviews began with a broadly open-ended question, specific to the purpose of the study: "How has the diagnosis of cancer affected your life?" This was followed by some more open ended probing questions such as "How has cancer affected the quality of your life, your relationship?"

Audio-recorder was used during the interview and field notes were recorded. Data was analyzed based on van Manen (1999) phenomenological analysis and personal experiences were transformed according to the four principles of existentialism, lived space (spatiality), lived body (corporeality), lived time (temporality), and lived other (relationality) to enhance understanding.

### Trustworthiness

Measures to ensure trustworthiness were applied. Guba's (Guba and Lincoln 1985) strategies of credibility, transferability, dependability and confirmability were implemented.

Credibility was increased by rephrasing questions, repeating questions, or paraphrasing statements to ensure credibility of information (Krefting 1991). Transferability was achieved by a dense description of the data and purposive sampling (Guba and Lincoln 1985). Prolonged engagement with participants increased the dependability of the research. To achieve confirm-

ability the researcher remained neutral by minimizing immersion of personal feelings in the conversation, without allowing bias or own perspectives to influence the conversations.

### Ethical Principles

Permission was sought from the hospital management and the ethical principles were applied as follows, participants' names were not identified throughout the study, and were interviewed privately in their comfortable places. All participants gave informed consent, full explanation of purpose, objectives and benefits were outlined prior the study. They can withdraw anytime without penalty.

## FINDINGS

Findings revealed that participants were uncertain of the future and prognosis of the disease. Participants were in search for information and cure which made them seek health care from the health system and cultural health system. Different systemic symptoms were experienced and pain management was inadequate. The participants further expressed feelings of being a burden to others and loss of self-concept as person by carrying the diagnosis of cancer as it reduced their quality of life (Table 1).

### Literature Control of Findings

#### *Theme 1: Lived Space Spatiality*

Patients with cancer mostly felt that they were no longer comfortable with their normal life space as they now find themselves in a health setting environment where they experience the environment as challenging. They experienced the environment as threatening and sometimes depressing.

#### *1.1. Feelings of Uncertainty*

The study highlighted the uncertainty that affects the person's live on daily basis, as they did not have clear cut answers to questions or a clear direction to guide one's life, they experienced fear, worry and anxiety. The participants reported that:

*"I wanted more definite answer about my situation and I did not get it."*

*"Fear keeps creeping in, I wonder what is going to happen, and will I be healed?"*

**Table 1: Themes and subthemes of the lived experiences of cancer patients**

	<i>Themes</i>	<i>Sub-themes</i>
<i>Lived Space Spatiality</i>	Living in the uncertain Fear of diagnosis, misdiagnosis and the unpredictability of the outcome or prognosis of the disease	Seeking information from health sector and indigenous knowledge system
<i>Lived Body Corporeality</i>	Eager to understand diagnosis Changes in body structure due to treatments and side-effects of medications Struggling with persistent pain	Enduring distressing discomfort- such as incontinence, sexual dysfunction, metabolic dysfunction- nausea and vomiting and skin changes Ability to maintain self- management of symptom to maintain quality of life
<i>Lived Time Temporality</i>	Bearing the diagnosis brings about uncertainties about the future Anxious about the future of the loved ones Do not see the value of continuing treatment or continue to while away time with treatment	Uncertainty provokes fear, which affects the self Developing an awareness of value for life e.g. formation of support group for social support Improving the self-concept to improve quality of life
<i>Lived Other Relationality</i>	Feelings of being a burden to others and family members Relying on others with activities of daily living (ADL) Regaining self-concept	Trusted family support is needed in the disease process- during treatments, diagnostic tests and other social issues Unwavering support experienced with health personnel- lack of open communication, fruitful explanation of the treatment plan

*“I feel tense and anxious, I am afraid of death.”*

Having cancer seem to involve uncertainties and perceived lack of control, which can be anxiety provoking. Living with each source of uncertainty is challenging because it may persist, waxing and waning, throughout survivorship and can affect one's worldview towards cancer. Uncertainties experienced by cancer survivors highlight the need to assist such individuals as they cope with the challenging changes associated with cancer survivorship. Vaartio et al. (2003) indicated that cancer diagnosis often comes as a major shock to the patients as it is an illness that is typically associated with fear, pain, hopelessness and death.

### *1.2. Fear of the Outcome/Prognosis of Disease*

Most of the patients diagnosed with a dread disease will be constantly anxious to know about the prognosis of the disease. Most of the participants reported their constant eagerness to understand and be informed about the progress of

the diseases, but they were mostly shut out, not getting full explanation. Here is what the participants expressed their fears:

*“Whenever you feel something irregular going on in your body, you start thinking, is it getting worse or what.”*

*“When I was taken a biopsy I was so restless, wanted to know what the results were, is it intense or better, it just worrying.”*

*“My life was torn apart when I was told my cancer was aggressive, and that i need to start chemotherapy..... hmm..... what does it mean?”*

*“I felt a sense of relieve after three cycles of chemotherapy, and I was told I am making progress.”*

*“The doctors were just talking about me, having my bed letter (meaning patient clinical record), not even asking me, just said: “we can amputate above knee” not realizing that I understand a bit.”*

The scientific approach to nursing reiterate that patients should be included in their care, designing their care plans, engaging them in the

implementation and evaluation of the care assist in establishing a good therapeutic regimen were the patient understands and adheres to treatment protocols, which relieves uncertainties and anxieties.

In the study patients had received reports about their conditions in an unsupportive manner. It is demoralizing to convey negative comments in the presence of patient about their tests results, the results should be conveyed in a supportive way, and they should be encouraged to verbalize or raise any symptomatic feeling they have so that they can be assisted, in allaying anxieties or uncertainties.

Sandeman and Wells (2011) also affirms the idea of maintaining a positive rapport with patients and having a supportive conversation during consultation as words often provided powerful affirmation of patients' hopes and expectations. These positive comments from the clinician have the potential to enable patients to re frame their own interpretations of their progress.

### **Theme 2: Lived Body Corporeality**

Patients experienced the physical, psychological and emotional discomfort, it is of utmost important that the patient be provided with holistic care so as to also address the emotional being in the person.

#### *2.1. Experiences of Symptomatic Discomfort*

Patients reported to have experiencing various physical and psychological symptoms such as pain, fatigue, depression, and anxiety. Some of the participants indicated the following:

*"I felt nauseas after chemotherapy treatment."*

*"I did not have the appetite, when I was eating it was like I am eating chalk."*

*"It does not feel good....mm..... (Muya wanga u dzula u fhasi)" implying that her mood is always low."*

*"I do not have the energy."*

*"I sometimes wake up with some slight swelling of my arm or face."*

Cleland (2015) is of the opinion that despite the increasing emphasis of the high-priority of symptom assessment and management, systematic reviews continue to indicate that pain

and other symptoms associated with cancer and its treatment are not optimally controlled. Many patients with more advanced cancer remain highly symptomatic, and many of these symptoms are the results of aggressive therapy.

Patients should be counselled on symptom management and control, so that they must be able to relieve themselves from the intensity of the symptoms. Also keeping a diary on the symptoms will assist in determining that the disease is progressing or not as symptoms can progress from mild to moderate.

Kang et al. (2014) also reported that symptom change can be expected to occur over time, and thus tracking these symptoms over time is important because of the dynamic nature of the phenomenon of cancer. Especially when the cancer trajectory approaches the terminal stage, symptom levels may be subject to change.

#### *2.2. Feeling Distressed Due to Physical Pain*

Paice and Ferrel (2011) describe pain as an all-consuming experience including physical, psychosocial, and spiritual dimensions. Cancer patients were dealing with side-effects of diagnostic measures, drugs and other forms of treatment. Some of them had this to say:

*"My whole body is aching; my muscles are so weakened that I cannot carry my body, why is God not taking me."*

*"I experience swelling, and it's terribly sore."*

*"Sometimes I feel reluctant to go for follow-up treatment its sore, especially when they place those instruments inside your private part, yoh! ndi tsipa (experiencing muscle spasm)."*

*"I cannot work full time after treatment, I feel easily exhausted."*

*"You just feel like crying at times."*

*"The pain is so severe that I cannot do anything for myself, I must rely on others."*

Pain impacts all dimensions of quality of life (QOL) and profoundly influences the patient's ability to endure treatment, return to health as a cancer survivor, or achieve a peaceful death. The cancer pain is constant and unrelieved. Participants in this study expressed fears and worry about the physical symptoms that accompany cancer, relating the intensity of the pain as making a person invalid. The findings concur with that of Doumit et al. (2007) reported that partici-

pants expressed their worries about their inability to cope with certain cancer symptoms, mainly pain. The fear of pain was sometimes greater than the fear of death itself.

Participants preferred dying instead of suffering from pain and that crying was not a shame, it is a way of expressing one's feelings. Cancer patients should be taught psychosocial interventions that are aimed at enhancing a sense of control over the pain or underlying disease.

### ***Theme 3: Lived Time Temporarily***

The physical and emotional pain experienced by cancer patients might place them on a continuum between life and death, where others will cherish past and present moments with loved ones, while others might not have hope for the future.

#### ***3.1. Bearing the Diagnosis and Uncertainty about the Future***

Cancer diagnosis places fear, anger and self-blame in individuals, cancer sufferers might think that something they did might have caused the disease. Bearing the diagnosis can be related to death sentence. Participants indicated that: *"having cancer was like a disruption in my life, my plans, my dreams were shattered"*

*"I felt empty inside, I kept asking myself, is it worth living."*

*"I was confused, will I be able to live a normal life again, and will things ever be the same again."*

*"Will I cope and be productive at work, what will happen if I can no longer work, my family looks up to me.....hmm, I am the breadwinner."*

*"Aa..... Vhone.... a huna thuso, kha vha hangwe" (implying Hey.... forget there is no help nor hope)."*

Cancer patients need to learn about cancer and their diagnosis in order to get an understanding of what they can do for their health and finding out about the services available for them can give them a greater sense of control. Having self-control of cancer can reduce the fears, anger, and guilt and have concrete answers and ways of adjusting to cancer. Sandeman and Wells (2011) reported similar findings with lung cancer patients who experienced uncertainty and unpredictability about what to expect

in the future, and it is clear that patients are often ill-prepared for what is ahead.

Maintaining a relationship with the oncology team appears to be important in helping patients at any stage of disease to cope with the uncertainty and vulnerability that ensues after a diagnosis of cancer. This is particularly the case when patients feel anxious and alone, in need of support to deal with the disease.

### ***Theme 4: Lived Other Relationality***

Human relations can built or alter cancer patients perspective towards the disease or provide hope. Cancer patients need to be made to believe that there is hope in treatment and can be able to survive by the support provided by the loved ones, health personnel the community.

#### ***4.1: Social Support***

Social support is an important factor when diagnosed with a chronic condition because a family becomes a source of anchor; they give moral support, take care of your physical needs and assist with the activities of daily living. Patients expressed positive aspects of support, they said:

*"I got a lot of love and support from my family, they were always there for me, when I am admitted, and they visit regularly."*

*"My siblings come and insist on bathing me when I am weak, saying they want to relieve my kids, they can spent a week post discharge just to see how I am fairing."*

*"Most of the time my wife assist me with bathing, and make sure that I eat even when I am reluctant to eat, she will insist on making something light (soft porridge) to eat."*

African communities have a network of family and neighborhood support, when a person is sick everyone within the family household becomes involved, similar circumstances were expressed by the participants that caring and support was not only contained in a nuclear setting, but was extended to outside. Cebeci et al. (2012) also emphasized the importance of family support in the process of breast cancer diagnosis and treatment and reported that participants were physically, emotionally and socially supported by their family members.

In addition, the majority of family members giving support, except spouses, were women.

In most societies women have been reported as primary carers, in rural communities caring is extended beyond the nuclear family, it involves, aunts, uncles, nieces and nephews, because in most circumstances relatives live within the same vicinity. African rural communities still have the ethos of Ubuntu.

#### 4.2. Sense of Guilt and Self-blame for Being Family's Burden

People with cancer and their families might feel guilty about their emotional responses to the illness. They might feel pressure to keep a positive attitude at all times, which is unrealistic.

Here is what the participants had to say: *"Sometimes you feel you are a burden when you rely on others for help."*

*"I could see that my family was suffering, they were trying to be supportive and wanted to help always."*

*"I felt bad at times when you find that people around you sort of minimize conversation when you are amongst them .....it's like they are conscious of not saying anything that may hurt you, the whole atmosphere becomes unnatural, the situation makes you feel uneasy and guilty."*

Being a burden to others can be overwhelming for an individual as they feel that they are trapped in their situations, and their privacy is somehow disturbed and are not given space to be themselves. Most participants expressed the fear of being seen as invalids who cannot do anything by themselves, with family members having to adjust and compromise their activities for your sake.

Senden et al. (2015) reported that participant felt an existential feeling of having lost one's identity. Participants struggle for independence was reflected by continuing to carry out their daily activities which could be framed within the idea that patients wanted to return to their customary life in order to minimize the impact of the illness. On the other hand, family caregivers felt themselves affected, not only as caregivers but also as persons. They experienced powerlessness by being a passive observer of patients' suffering. Being a burden has multiple implications as it affects the emotional and psychological being including guilt, sadness, and self-blame.

#### 4.3. Multidisciplinary Health Support

Experiencing support from the multidisciplinary team is a complex situation of human nature, some health professionals were found to be supportive, others did not show concern or respect for the human dignity. Some of the participants had this to say:

*"Sometimes I felt isolated and alone as nurses' passes without acknowledging your presence; just a mere good morning is enough"*

*"Whenever you are referred from one department to the other is a problem, they just direct you, with no one to accompany you"*

*"Sometimes you find new faces, the doctor that saw you last time is not the one and you are reluctant to ask questions because even the consulting nurse is impatient, looking at the queue"*

*"It looks like everyone is doing her own things, there is no co-ordination, when I was referred to x-ray, I waited for about two hours without any information of whether the doctors are available or not, and I felt nauseas and ate an avocado, the procedure was cancelled, I was given another date, yoh..... I was not even told that when you come you must not eat."*

These are everyday problems in health facilities where patients meet different health practitioners, especially in rural public hospitals where doctors are not permanent, they are either visiting specialists or on contract. Lafferty et al. (2011) reported that women diagnosed with breast cancer felt that continuity was lacking in follow-up clinics and 67 percent felt they did not have sufficient time to raise emotional and informational needs as the consultation was more focused on the physical aspects of care.

Patients emphasized the importance of being treated as an individual rather than a number, that health personnel should show interest in them as a people. Patients also reported that they valued having a named person to relate to throughout their cancer journey. Similar situation occurs in the rural public hospitals in South Africa, cancer support still lacks behind as there are not enough specialists and oncology nurses who can be able to navigate the patient throughout the cancer journey. There is fragmentation of services as most hospitals cancer patients are admitted in the general medical and surgical wards.

#### 4.4. Regaining Self-concept

Early palliative care improves quality of life and decision-making in patients with advanced cancer and may improve survival. Patients expressed a positive view to quality of life, here is what they said: *“I felt much better because when I started treatment I was anxious and afraid, but when I saw how many people were coming for treatment I became less anxious to say I was not alone in this.”* Another one said this confidently: *“I started treatment for my breast cancer, and my breasts were removed, can you notice that? (showing by means of palpating), so I tell people everywhere about checking their breast so that they must go for treatment early.”*

To regain one's self-concept a lot of support is needed, as some patients become depressed and drown in their own pain and sorrow when they lacked support, moreover palliative care is not well established in rural communities, as patients are still cared by their immediate and extended family members, thus social support enhances the self-concept.

Having a positive spirit to life, having the subconscious mind thinking positively, makes the conscious person react positively, positive thoughts benefit the self-concept. Findings concur with Cebeci et al. (2012) who reported that participants expressed a greater appreciation of life and that cancer diagnosis brought the positive change in the patients' worldview, they indicated that they felt more connected to life after their diagnosis and treatment.

McCorkle et al. (2011) tested the effects of a self-help intervention protocol (SHIP) in women with breast cancer undergoing adjuvant treatment, the purpose of which was to increase knowledge about cancer, improve problem solving, redirect negative thinking, promote effective communication with health care professionals, and minimize uncertainty. Capacitating patients with self-help activities related to their therapeutic regimens and lifestyle modifications can assist patients to have a quality of life irrespective of the cancer diagnosis.

### DISCUSSION

Having cancer seem to involve uncertainties and perceived lack of control, which can be anxiety provoking. Participants described sources of medical, personal and social uncertainties

which often lead to anxiety states and can affect the quality of life. Most of the participants were worried about prognosis and future health; they had constant questions about their treatments that were not answered. This suggests a lack on the part of health professionals regarding communication and reassurance on the treatment regimens and the ability to cope with side-effects.

It is therefore imperative that follow-up treatment should provide opportunities for reassurance, patients should be provided with information about every single step or medical management so as to reduce uncertainty and for the person to reconcile with reality. Cancer management in public health institutions is poor and lacking, and cancer patients are left helpless as there are no sufficient oncology teams in district or regional hospitals. Oncology nurses are not able to support cancer patients as they are short staffed and have to meet targets placed by the departments for awareness and specific campaigns.

Provision of holistic care is inadequate because even the referral system is sometimes distorted and patients end up disappearing in the system due to lack of proper follow-up management and inadequate community services programme for oncology. The social support from friends, relatives and health care professionals were important for psychosocial adjustment and survival of cancer patients.

Health services need to coordinate their services so that follow-up should not be discouraging for patients by avoiding long queues, having messengers to run errands for patients and have enough resources because patients get lost in the process of going from one department to the other for services. Participants also experienced symptoms differently, as pain can disrupt the quality of life as it result in perceived loss of control, pain caused physiological as well as physical harm to the patients. Pain management should be comprehensive to include total pain, including the psychological, social and spiritual factors not only the physiological component, this will enhanced the quality of life of patients.

Patients were sometimes discharged with large doses of pain medication without intensifying other pain control mechanism, health promotion seems to be limited. Cancer patients should be assisted in improving their quality of life, so that they should not view themselves as

invalid because once a person is diagnosed they insist on getting social grant for their illness, a change of perception is necessary for the patient to regain their self- concept.

### CONCLUSION

Improved education is needed for patients and must incorporate in their individualized care plan so that they are able to manage health problems associated with cancer diagnosis. Incorporating family members in treatment plan can also be beneficial to be able to assist and give moral support. Follow up and communication techniques and approaches are important in maintaining doctor/nurse- patient relationship, how information is discussed and conveyed impacts on subsequent visits and problems with continuity of care relate to managerial issues current clinic organization and management which result in lengthy waits and short consultations, particularly at follow-up.

### RECOMMENDATIONS

- The oncology nurses assisting patients during consultation should allow more time for consultation in order to address uncertainties and be culture sensitive.
- Follow-up should be comprehensive, in answering questions in simple clear language for patients' comprehension and understanding.
- Reducing the waiting time of patients to be seen at oncology clinics and making prior arrangement of making files easily accessible.
- Reducing the time patients wait at the clinic for diagnostic tests/results or provision for messengers to send specimens for diagnostic tests.
- The provision of refreshments during waiting sessions.
- Health education and health promotion should be intensified to improve the quality of life of patients in maintaining healthy lifestyle, and symptomatic management.
- Proper counselling about diagnosis is important and referral to appropriate community services for psychological and emotional stability.

### ACKNOWLEDGEMENTS

The author pays special thanks the patients who participated in this study for their valuable contributions.

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