



# Hope for the Best, Prepare for the Worst: Phenomenological Exploration of Cancer Patients' Lived Experiences

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## Abstract

Cancer stands as one of the most devastating and leading causes of mortality globally. Cancer is still a major public health concern in Pakistan, as it significantly raises death rates throughout the entire country. The occurrence of many cancer types has been increasing, resulting in an immense burden on the healthcare structure. This research aimed to explore how cancer patients maneuver their daily lives while battling the illness. Utilizing a phenomenological research methodology, in-depth interviews were conducted to gain insights into the perspectives of cancer patients. The data was collected from a sample of 15 hospitalized patients at the Institute of Nuclear Medicine, Oncology, and Radiotherapy (INOR) Hospital in Abbottabad, Pakistan. Thematic analysis (TA) was employed to examine the interview transcripts, revealing several key themes. These themes encompassed the patients' experiences with cancer diagnosis, the impacts of cancer therapy, psychological effects, social support, and the significance of spirituality in their healing journey. The study's findings underscored that patient faced specific challenges upon receiving their cancer diagnosis, along with psychological stressors such as uncertainty, social isolation, and the side effects of treatments. Notably, patients discovered that spirituality and religious practices served as effective coping mechanisms to alleviate the unpleasant effects of cancer. Based on the study's outcomes, it is recommended that healthcare professionals take into account the patient's experiences and consider the role of spirituality and spiritual practices in enhancing the well-being of cancer patients. By understanding and acknowledging these aspects, medical practitioners can potentially improve the overall care and support provided to cancer patients during their arduous journey of battling the illness.

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## **Introduction**

Cancer stands as one of the most lethal diseases globally. According to the World Health Organization in 2020, there were approximately 10 million cancer-related deaths and 19.3 million new cancer cases worldwide (World Health Organization, 2021). In the United States, the risk of receiving a cancer diagnosis is significant, with one in four individuals facing a lifetime risk of cancer (Ben-Ayre, Steinmetz & Ezzo, 2007). In Europe, cancer accounted for 1.7 million deaths (Versano, 2011), and projections indicated that this number might double by 2020 (Eaton, 2003). The burden of cancer in Asia was also substantial, with 2 million fatalities and 3 million new cases reported in the same year (Mackay et al., 2006). In Pakistan, the situation was no less alarming, with a total of 178,388 new cases reported in 2020, and cancer-related mortality rates on the rise (International Agency for Research on Cancer, 2018). The prevalence of cancer is on the rise, but there is still limited knowledge about the lived experiences of patients and the complex circumstances that surround their condition. Patients' experiences are shaped by various factors, including sociocultural, psychological, religious, financial, demographic, and physical effects of the disease, as well as their knowledge and perception of cancer. Exploring these experiences can offer valuable insights into the unique healthcare requirements of cancer patients and aid medical professionals in delivering competent and supportive care. This study aimed to gain a deeper understanding of the experiences of Muslim cancer patients diagnosed with cancer at the Institute of Nuclear Medicine, Oncology, and Radiotherapy (INOR) in Abbottabad, Khyber Pakhtunkhwa, Pakistan. By exploring their perspectives and challenges, the research aimed to contribute to a more comprehensive understanding of cancer care and support tailored to the needs of these patients.

However, a significant amount of study has been done on a variety of topics relating to cancer patients' experiences. Scientists argue that patients experience a greater degree of distress and grief due to the endless nature of cancer growth than from other illnesses (Meyerowitz, 1980). Additionally, it consists of fear of dying, social humiliation, sadness, low self-esteem, and anxiety (Harmer, 2006). It simultaneously brings feelings of isolation, ambiguity, the possibility of a cancer return, and financial difficulties. In the

end, it results in despondency and a reduced standard of living (Heidarzadeh et al., 2014). In a qualitative study using phenomenological approaches, Smith and Johnson (2018) dissected the complex layers of the subjective experiences of cancer patients. Their findings highlighted the transforming character of the cancer experience by revealing the tremendous influence of the illness on people's sense of time, self-identity, and relationships. Moreover, in an investigation by Anderson and Clark (2022), existential difficulties encountered by cancer patients were explored using phenomenological approaches, with a focus on the altering influence of the disease on the patients' sense of self and identity.

According to an interview with American breast cancer patients, women expressed concerns about their bodies, hair damage, feeling unbalanced in their attire, and the absence of prosthetics that matched their skin tone (Henderson et al., 2003). Another discussion with 20 black and South Asian ladies voiced concerns about cultural stigma and restrictions surrounding cancer. Breast cancer also harmed their femininity, physical appearance, and sexuality, and they expressed concerns about their skin and hair (McGarvey, 2001). Additionally, the effects of demographic variables on cancer patients vary. According to Tercyak, Davis and Loffredo (2007), stage 4 breast cancer in younger patients was associated with increased anxiousness and despair. Children and single breast cancer patients have also been linked to higher levels of melancholy and despair (Friedman et al., 2006). In terms of the physical effects of cancer, patients who have undergone surgery or chemotherapy may have physical weariness and impairment (Brandberg et al., 2003), which may interfere with their ability to go about their daily lives and perform their jobs (Moradian, Aledavood& Tabatabaee, 2011). Additionally, breast cancer's horrific physical side effects include extreme weight loss, body weight, and general exhaustion (Helms, O'Hea& Corso, 2008). Additionally, a course of treatment like chemotherapy can cause patients to experience another cycle of emotions like anger, denial, guilt, and despair in addition to affecting other psychosocial functioning domains (Holland & Zitton, 1991). In addition, surgical therapy for breast cancer has negatively impacted females' physical allure as well as components of romantic connection. Females who were single at the time of surgery were concerned that the condition would make them less physically attractive and prevent them from engaging in romantic relationships. Females who were already in a relationship or who were married, however, expressed concern that their loving partner would no

longer find them physically appealing and desirable due to surgery (Oxlad et al., 2008). This results in a loss of self-assurance and life goals, which impacts not only the physical body but also the battling spirit and soul. Owing to expending so much energy on dealing with diagnosis and treatment, they frequently reach the point where they feel hopeless and extremely frightened. In this case, the patient is going through unusual and difficult circumstances (Villagomez, 2005).

## **Methodology**

This study uses a phenomenological research methodology to describe cancer patients' experiences. The rationale behind the use of phenomenology as a research method for this study is that it is particularly suitable for exploring people's subjective experiences. Phenomenology turns out to be a perfect fit for this study since it allows for a detailed examination of cancer patients' lived experiences, probing their thoughts, feelings, and ways of giving meaning to their events. Focusing on the first-hand experience, phenomenology allows for a thorough understanding of the complex and varied ways that people negotiate and make sense of their experiences with cancer. This methodology is in perfect harmony with the research objective of encapsulating the rich facets of participants' experiences, providing insightful information about the psychological, emotional and others elements of dealing with cancer.

Due to the nature of the phenomenon, an in-depth interview was decided to be the best method for gathering data. Recruitment of cancer patients who are currently getting treatment, have been diagnosed with the disease, and are physically able to engage in an interview was done using a purposive sampling technique. The principles of data saturation were used to guide the data collection. After the fifteenth interview, no emerging themes were discovered. The final sample size was composed of 15 Muslim participants, 10 of whom were men and five of whom were women. Members were free to choose the terminology and open up about their personal histories. While some of the participants preferred to voice their opinions in Pashto, most of the participants preferred to be interviewed in Urdu. Each interview was audio-recorded and lasted between 40 and 60 minutes. The confidentiality of their responses was ensured by the researcher. Braun & Clarke's (2006) inductive thematic analysis was used to examine the data. Each text (interview) was carefully read numerous times while notes were being taken.

The first step of the theme analysis approach was to fully immerse oneself in the facts in order to gain a thorough comprehension. The author then created preliminary scripts to emphasize important concepts and aspects in the dataset. After then, these codes were grouped into prospective topics and subjected to an ongoing process of improvement and scrutiny. After that, the author named and defined the themes that had been found, making sure that they accurately reflected the context and substance of the material. The last step involved crafting a story that made sense, in which the writer analyzed the themes and provided a sophisticated interpretation that matched the goals of the study. Consequently, five key themes emerged from the analysis of the participant narratives, including experiences with a cancer diagnosis, the effects of treatment, the psychological effects, social support, and the importance of spirituality in healing. Each concept is succinctly explained and supported with illustrative quotes.

**Table 01: Participant Demographic Information (n =15)**

Gender	Age	Marital Status	Cancer Type	Cancer Stage	Treatment	Time Since Diagnosis (In Months)
Male	60	Married	Colon	Stage 0	Radiotherapy	26
Female	45	Married	Breast	Stage 1	Mastectomy	18
Female	33	Single	Breast	Stage III	Chemo/Tamoxifen	16
Male	65	Single	Lung	Stage II	Chemotherapy	11
Male	61	Married	Lung	Stage II	Radiotherapy	19
Female	38	Married	Lymphoma	Stage II	Radiotherapy	22
Female	27	Married	Colon	Stage 0	Palliative Chemo	9
Male	29	Single	Liver	Stage IV	Chemotherapy	12
Male	41	Single	Liver	Stage I	Radiotherapy	26
Male	33	Single	Colon	Stage II	Radiotherapy	4
Male	51	Married	Gastric	Stage II	Mastectomy/Ra	14

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Male	24	Single	Prostate	Stage 0	Chemotherapy	4
Male	29	Married	Lung	Stage II	Radiotherapy/ Chemo	10
Male	36	Single	Throat	Stage IV	Chemotherapy	28
Female	47	Widow	Cervical	Stage 0	Mastectomy/ Chemo	17

## Study Findings and Discussion

### 1. Cancer Diagnosed Experiences

Cancer growth is the most widely recognized type of lethal illness; particularly in the Western world highest cancer ratio was recorded (Radice & Redaell, 2003). Cancer is usually perceived as a crisis and chronic situation for a patient. When diagnosed with cancer, the patient passes through various circumstances that alter the patient's perception toward disease and health care. Furthermore, it also dramatically disturbed everyday life and specifically more unexpectedness of a cancer diagnosis; the strength of cancer and the terror of premature death all add threats for a patient. This theme outlines the views of patients.

**Interviewer:** How did you encounter your disease at the time of diagnosis?

*For the past eight months, I have had a lung cancer diagnosis. I've been smoking for the past ten years with joy and enthusiasm, enjoying every puff of every cigarette. After a moment of brief ecstasy, I fall victim to a protracted infection that lasts forever, and lung sickness causes all of my joy to be snuffed out. At the very first chance, I felt ordinary temperature, coughed, and became weak, feeling pain and vomiting. When I visit a doctor for a checkup they conduct some medical tests and diagnose me as a cancer patient. From that time, I detest myself, my way, and my life, since I am suspicious of life and death.*

Diagnosed with cancer, patients face a traumatic condition that brings long-term changes in patients' overt and covert aspects of their health and lifestyle. It alters questions about life and ultimately a substantial shakeup occurs in one's life, interactions, and objectives, as well as the renovation of a novel self-identity. One other participant said:

*I was given a throat cancer diagnosis. My friends told me that there was nothing more that could be done for me in terms of surgery or treatment. You just have three to four months left to live. You will lose all of your money and get nothing in return, but I still have courage and confidence. I shall begin treatment. I observe that cancer carries changes in a patient's life, in my status and role. In that context, a patient has working incapacity, household and personal stress, isolation, humiliation, and loss of self-identity in public. Because all illnesses are the same for the patient, there is no difference between chronic and transient illnesses. Currently, I am generally looking for ways to improve my health and am willing to travel far and wide if there is a solution, but I have never experienced such light. I now have complete control over my disease and agony.*

Another respondent shared their early experiences as a beginner about the disease.

*At the first visit, the doctor diagnosed me as a cancer patient. The disease alters and influences a patient's profile (physical, mental, and functional), which then contributes to the growth of cancer. Alas... .!!!! Every day isn't any less of a gift because it harms and interferes with every element of the patient's life. I monitor my infection every second and in a split second. The first and most noteworthy thing I have found in my disease from the beginning, I feel fear and apprehension about this unsafe disease.*

Cancer and such chronic diseases are stressful for all patients. At the time of diagnosis, patients have some psychological issues such as irritability, rejection, fear of disease, and disheartening from their existing

situation. But on the other side, they don't become sitting restless, they practice some measures for the disease to cure and improve their quality of life.

## 2. Effects of Treatment

For many patients, the treatment has negative side effects which further influence their quality of life. During or after treatment, the patient is enclosed with feelings of despair, irritation, and frustration, which further increase and generate many other physical, psychological, and social effects.

*When I got treatment (chemotherapy, radiation, and surgery) I felt pain, and losing the sense of taste and hair was evident. I was unable to perform household duties. I plan some methods to avoid hair loss by wearing a cap but can't do so. It's Okey. After treatment, I feel somewhat good and cheerful, however since that day I heard that an individual was diagnosed as a breast cancer patient. My heartbeat turns out to be high because of the more terrible name and due to my awful encounters. I utilized some house-made medications with such expectation that they may mend my tumor. However, that treatment has not demonstrated accommodating for me. After treatment, the half-life of a patient is gone. Physically patient becomes fragile, and feels hate and shame. Sometimes, I was thinking of death, because death is better than this life.*

The study of Gates, Lackey and Brown (2001) shows that breast cancer patients have impacts on their bodies and feel that they have lost a significant part of their body. Women felt that wearing breast prostheses helped them to defeat their self-perception concerns and recover their body shape. But they no longer felt stable and whole human which caused less feeling of femininity. One of our respondents shared that:

*I've had breast cancer for a year now after receiving my diagnosis. After that, it extends to the lungs. There was first a bulge, which grew in size. My sister disclosed to me that cancer has no cure. As the tumor got greater another hyper*



*assault and surrounding me was a breathing issue. At that phase, I gave more inclination to clinical preliminaries, for example, X-rays, chemotherapy, radiation, and medical procedures, and afterward in conclusion cut my left breast.*

Another participant used some traditional and domestic methods of treatment. They expressed their views.

*I practiced household tips, however futile. Some people say, to use fig and Kalwanji you will recoup soon. It is the best medication for all diseases apart from death. I utilized it, yet, at that point, I didn't have faith in it and felt that individuals are alive till to their victuals are completed. Then proceeds to die from this awful and depleted life. I do not pay attention to this infection, even though I have pain. I believe that humans are born in pain and for illnesses. The various diseases created for humans and that is normal. Each human has one or other kind of sickness in their life.*

A few patients likewise communicated the sentiment of body consciousness, particularly when going out in public thus, it restricted their social movements. Such sentiments were increasingly conspicuous during the time females used their medicines. However, after some time patients acknowledged their modified appearance sentiments turned out to be less. The level and nature of appearance were dependent on the category of social support and treatments that patients get.

### **3. Psychological Effects**

The psychological effects highlighted by many researchers, they had acknowledged that often the psychological issues have been more severe than the physical impacts (Neil & Barrell, 1998; Sen, Ross & Rogers, 2001). In those issues, patients feel depressed, nervous, and uncertain, and have difficulty with the fear of the recurrence of the disease. As pointed out by the participant:

*After diagnosis, my life was occupied by fear, threats, and the cancer itself pandemic disease. The lethal title makes a*

*patient more susceptible to the survival of life. If I take this illness seriously, all I can do is get more anxious and put myself under more stress, which compromises my life and health.*

Enoch and Price (2004) reported that, for the majority of patients, it was generally not a disease that affected them but the psychosocial concerns related to it drastically influenced their quality of life. Another respondent talked about their condition:

*This situation is multiple of my anxiety and devastation, [weeping and crying.....]. I am desperate because a single cough is equivalent and a sign of disease. And then cancer..... relatives and other society members hate from a cancer patient. Along with this if a patient is not whole (means cut a part of their body, e.g. breast, leg, or others) people consider it a disability. Due to this, a patient considers themselves lower-class humans and can't participate in any social gathering. If go to some social activity people go far away and hate them. But I am still in terror that this will rash again and send me to the bed of the hospital.*

The study of Zabora et al. (2001) found that patients experience physiological issues and their impacts are more severe than others. Because it gives birth to feelings of uncertainty about the future, and psychological and emotional distress, which affects the physical, social, and spiritual aspects of a patient's quality of life. Additionally, the study concluded that it also affects patient perception toward treatment and affects all sorts of healing and treatment mechanisms.

#### **4. Social Support**

Both interpersonal and intrapersonal means are vital for coping with disability and illness (McCull & Skinner, 1995). It becomes obvious that support, predominantly from household members' friends was very significant in facilitating a patient's diagnosis and treatment. One of the participants declares that:

*I became glad... .. more joyful... .. from myself, my household, and even the healthcare specialist to give me the finest level of medical treatment and emotional livelihood. Believe it, presently I feel better and proceed with my day-by-day life routine as previously. I don't take it seriously. Because my family members highly support me in all respects during my illness. I relish my life in both conditions and it is the best prescription for all illnesses.*

Family members were labeled as providers for everyday support such as taking hospital arrangements, facilitating domestic tasks, and supporting other daily activities such as bathing or brushing hair and many other tasks. The study by Henderson et al. (2003) found that patients relied on family, church members, and friends for help in coping with a diagnosis of cancer.

*From that time, I was so dismal, stressed, and sobbing and didn't eat for two days at all. I feel become weak physically. My husband, child, and little girl empowered and revealed to me that it isn't a lot more concerning issue, all will be Okay but it will require some time.*

Other participants highlighted intrapersonal resources. They depicted that confidence in God was a significant source of help and taking part in religious activities, such as praying and holy readings can help them. As the respondent mentioned:

*Disease as being God's will, I accept that God would invigorate me. My spiritual and religious practices are also helping me. But I also make use of treatment.*

For a cancer patient, intrapersonal resources include having faith, and spirituality, as well as activities such as meditation and yoga are supportive factors (Trinkaus et al., 2011).

## **5. Role of Spirituality in Healing**

One of the main and distinct themes that seem from all cases in this study was the significance of spirituality and its role in coping. This helps a

participant cope with tricky emotions, such as fear, sadness, and hopelessness. Participants identified the role as:

*Of course, spirituality is the centerpiece of a patient's recuperation. I more watch out for spirituality than clinical medication. If I say that I am pleased with my disease it's not off-base. I am imagining that God makes me capable of this disease and through this, I go to paradise. Humans are a lot materialistic and put stock in the material and see marvels, yet spirituality and religion are beyond this clarification.*

Another participant also highlights the significance of spirituality which offered comfort and eased his disease:

*For those who seek their healthiness in spirituality or spiritual practices, God heals them. Although God hasn't sent a sickness until a fixed cure if an individual cannot get healed it doesn't mean that spirituality misses the mark no..... no, everything is fixed, and when the hour of mending happens a patient gets recovered. Spirituality is the need of humans and nothing without it. I am not baffled by myself. These all (healthiness and disease) are in my fortune.*

Spiritual beliefs and practices strengthen a patient during and after treatment. Patients who have dominant spiritual beliefs and practices can easily heal.

*We enter this world with inherent vulnerabilities. Life and death are under God's control, following a predetermined timeline. When my prayers seemingly go unanswered, I experience discomfort; prayers act as a form of medicine. Additionally, I also utilize physician-prescribed medications. Though these medicines are man-made, it is God who grants humans the ability to create remedies for healing. During periods of good health, I must admit that I sometimes neglected my spirituality compared to my current circumstances. As I approach the end of my life, a common human response is to turn toward spirituality and seek solace*

*in faith when faced with the fragility of life and its uncertainties. It is natural for individuals to reevaluate their spiritual connection and draw nearer to God when confronted with such sobering realities. In these moments, they often find themselves on a path of self-discovery and spiritual awakening. [Laughter follows as an expression of this profound realization...]*

Spirituality has numerous benefits and is key for cancer patients coping to mend their quality of life through various spiritual practices (Matthews et al., 2012). Spiritual activities including prayer and attending church are a protective factor against cancer patients' illness (Janiszewska et al., 2008). Consequently, they were praying more and reciting the holy book and felt it was an instrument for facilitating them to treat and deal with cancer. As a respondent shared:

*I engage in daily prayers, perform a special rosary, recite sacred verses, and drink holy water (Zam Zam) to seek healing for my illness while maintaining unwavering faith in God. These spiritual practices play a significant role in my life, providing emotional gratification and an overall sense of improvement. When I miss my prayers or devotions, I sense that something is amiss. I also seek relief through medical treatment, which is considered a [Sunnah] in our faith. In some instances, patients find healing through the expertise of medical professionals, and I believe that God has endowed physicians with the power to cure. Therefore, I place my trust in both faith-based practices and medical interventions, recognizing the complementarity of these approaches in pursuit of better health.*

Spiritual practices are a source of coping for cancer patients. They focused on it to find meaning, and get satisfaction and healing through these practices. A prior study by Gibson & Hendricks (2006) described that beliefs and prayers have given the power to overwhelm terror and other challenges in their lives. As mentioned by a patient:

*Each morning, I engage in prayer and recite the Holy Quran to seek relief from my illness. I earnestly beseech God for support and healing, fervently requesting to be freed from this ailment. I maintain hope that I will ultimately succeed in overcoming this challenge. If it is God's will, I believe that recovery will come soon.*

Various spiritual practices influenced patient experiences and facilitated them to understand their illness and treatment through it. Spiritual applications prove helpful and powerful mechanisms in the prevention of an illness and decrease negative outcomes. Cancer patients reported that spiritual practices as a coping strategy for them to overcome the fear of disease, death, and psychological issues (Ashing-Giwa & Ganz, 1997).

## **Conclusion**

This study highlights the unique and profound impact that living with cancer has on patients, fundamentally altering their perspective on life. Understanding this phenomenon becomes crucial for both patients and healthcare professionals. The findings reveal that upon receiving their cancer diagnosis, patients faced overwhelming emotions and unexpected challenges, leading to transformative changes in various aspects of their lives. These changes encompassed shifts in body image, self-esteem, and social relationships. The patients' experiences were marked by numerous uncertainties, including anxiety and fear of death throughout their illness journey. Furthermore, the treatment process left them feeling vulnerable, contributing to physical and socio-psychological issues. Despite the adversities they encountered, the study found that patients exhibited optimism and drew strength from their spiritual beliefs, practices, and social connections. These factors served as vital sources of support and positive coping mechanisms in dealing with their illness. The research underscores the significant role of spiritual care and spirituality in the healing process. Consequently, the study's results could provide valuable preliminary evidence, offering guidance to healthcare professionals such as doctors, nurses, and counselors in delivering effective care and managing cancer more effectively. By understanding the unique experiences of cancer patients and recognizing the importance of spiritual and social support, healthcare

providers can enhance the quality of care and support provided to individuals facing this challenging journey of living with cancer.

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