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Lived Experiences of Cancer Patients Who Chose to Stop Receiving Treatment

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ABSTRACT

The study aimed to understand the lived experience of cancer patients who abandon treatment. Four semi-structured interviews were conducted, and the data was examined using interpretative phenomenological analysis. It resulted in four superordinate themes: (i) ‘Lack of knowledge about cancer’ dealt with patients’ knowledge and perceptions about their cancer. (ii) ‘Hopelessness with oneself and God.’ (iii) ‘Distress caused by numerous cancer-related issues’ captured the challenges faced by cancer patients. The last superordinate theme, (iv) Patient dissatisfaction with physicians and treatment’ dealt with cancer patients’ interaction with and expectations from their oncologists and the medical staff. It was found that these factors played a crucial role in treatment abandonment. The decision to discontinue treatment can be attributed to patient dissatisfaction with the physician and treatment. This dissatisfaction was caused by misinformation about the disease, treatment, and distress. Since the patients were familiar with each other as they went for chemotherapy in the same hospital, the decision to abandon the treatment of one participant may have influenced the other participant. For policymakers, it is critical to understand that a ‘dissatisfied patient’ may abandon treatment at any time during their cancer trajectory, consequently affecting the mortality, morbidity, and economic burden of the country.

Keywords: Patient experience, Treatment abandonment, Interpretative phenomenological analysis

1. Introduction

Cancer patients’ quality of life and survival have significantly improved due to recent advancements in cancer therapy.1 Despite these advancements, cancer is still the leading cause of death worldwide. In 2020, there were over 10 million cancer-related deaths worldwide.2 The estimated amount of cancer cases in India for the year 2022 was determined to be 1,461,427, with a crude rate of 100.4 per 100,000 population, and is expected to increase by 12.8% in 2025.3 Several challenges are being faced by the medical fraternity in the treatment of cancer in India, such as misconceptions about treatment,4 misconceptions about the disease and its causes,4 delays in diagnosis and treatment due to Traditional, Complementary and Alternative Medicine (TCAM) and nonadherence5 but the major challenge in cancer therapy is treatment abandonment. According to Chandrana and Pai,6 the dropout rate only at a tertiary care hospital was 17.54%. A study conducted in the Regional Cancer Centre, Thiruvananthapuram, Kerala, by Paul, George, and Mathew7 found that the dropout rate was 12%. These result in low survival rates and increase the economic burden on the country.

1.1. Traditional, complementary and alternative medicine (TCAM)

TCAM typically refers to medical procedures not provided by licensed clinical professionals or within hospital settings. The term “traditional medicine” (TM) describes indigenous local practices and belief
systems that are primarily applied to health issues in underdeveloped nations. The term complementary and alternative medicine (CAM) is commonly used to describe a variety of non-traditional, non-indigenous therapies, such as herbalism, homeopathy, and naturopathy. According to Yadav, Pandey, and Singh, 38% of households reported visiting TCAM practitioners, of which 40% belonged to rural areas and about 30% to urban areas of India. TCAM was preferred by participants because of its less expensive and had fewer adverse effects.

1.2. Adherence

Adherence is “the extent to which a person’s behavior, such as taking medication, following a diet, and executing lifestyle changes, corresponds with agreed commendations from a health care provider”. Studies on adherence report that patients often do not comply for various reasons. Some treatment regimens require patients to change their long-lasting habits, the treatment regimen itself is full of complexities, and clients with serious illnesses are less likely to adhere than those with milder health problems. It also depends upon the perception of the severity of the illness; patients with chronic illness, having milder symptoms, tend to adhere less. Lastly, compliance tends to decline over time. A few patient-related factors are also responsible for nonadherence, such as age, gender, and socio-cultural factors. For Indian cancer patients, age, gender, stage of cancer, toxicity due to treatment, and distance from home to hospital were associated with nonadherence to treatment.

1.3. Treatment abandonment

Treatment abandonment includes two key elements: (1) failing to complete therapy for a disease that could be cured or definitively controlled, and (2) missing all treatment for a sustained period to an extent that impacts the ability to cure or definitively control the disease. It is associated with several factors, including advanced disease, marriage, a lack of university education, socioeconomic status, symptom relief, and surgical fear. Treatment abandonment in India has been associated with high-cost private cancer care, old age; marriage, earlier age of illness onset, longer illness duration, less supervision for medication at home, continued symptomatology; a negative attitude toward medications; poorer insight; poorer adherence; and a poorer therapeutic alliance and advanced cancer stage. These are quantitative research studies that can identify the correlates of treatment cessation. Why patients discontinue their treatment is still unknown. Qualitative research was required to gain insights into patients’ perspectives and circumstances responsible for treatment abandonment. Therefore, the present study seeks to comprehend the lived experience of Indian cancer patients who discontinue therapy.

2. Method

2.1. Participants

Participants were selected using the snowball sampling method. The sample comprised four patients aged 19 to 40, including two men and two women.

2.1.1. Inclusion criteria of the sample

The participants were recruited based on the following criteria:

1) The patients must be older than 18 years of age.
2) He or she must be aware of the diagnosis.
3) No physical or psychological comorbidity should exist.
4) Patients must have received cancer treatment at the cancer hospital.

All four participants belonged to the rural backgrounds. All these patients stopped treatment without their healthcare provider’s recommendation. Patients B1 and O1 stopped their treatment after the first round of chemotherapy. In contrast, patient P2 underwent one round of chemotherapy, then surgery, and then another three rounds of chemotherapy, after which he decided to abandon treatment. Patient P1 stopped his treatment after undergoing surgery and the first phase of radiation therapy.

Ethics: The approval for the present study was sought by the Institutional Ethics Review Board. Participants were informed orally and in writing; their data will be strictly used for research purposes and kept confidential. All patients provided written informed consent prior to enrolment in the study.

2.2. Interview

Face-to-face interviews were conducted. The semi-structured interview schedule was divided into two parts, the first covering demographic data and information on disease and therapy. Questions about the experience of the sickness were included in the second segment. The interview schedule explored the treatment patients underwent and the reasons for abandoning treatment. These inquiries were made to
gain a thorough understanding of cancer patients’ experience of treatment abandonment. The main goal was to comprehend this experience as a phenomenon, to comprehend how people view cancer, what knowledge they have of it, the suffering they go through, and the reasons why they do not want any more therapy.

### 2.3. Procedure

The participants were contacted via telephone; however, they already knew they would be approached due to the knowledge of other participants. At the initial encounter, the participants were briefed on the purpose of the study, and rapport was established. They were informed that the interview would be audiotaped and assured that it would not be shared with anybody and would be used solely for research purposes. After participants granted their consent to participate in the study, they were asked for their addresses so the interview could occur at their homes or wherever they were comfortable.

The interview sessions ranged from 45 minutes to 1 hour and 15 minutes. Each interview took three to five sessions. The interview schedule guided the interviewing procedure. The initial phases of the interview focused on the participant’s background information, including his or her family history with the condition. In contrast, later sessions focused on the therapy he or she underwent and their reasons to stop the treatment. These questions assisted in gaining the participants’ interest and participation in the interview.

### 2.4. Data analysis

Pietkiewicz and Smith’s 23 Interpretative Phenomenological Analysis (IPA) was utilized to analyze the data. It is founded on phenomenological, hermeneutical, and ideographical tenets. In IPA, researchers attempt to fathom what it is like to be in the subject’s shoes and, through interpretative activity, translate the meaning to make it more comprehensible. The IPA is frequently concerned with the double hermeneutic or dual interpretation process involving participants and the researcher. The participants interpret their reality before the researcher attempts to make sense of that interpretation.

For IPA, it is usually recommended that the interview be recorded on tape. Therefore, each audio-recorded interview was transcribed verbatim (including pauses, tears, and laughter), and a code was issued to each participant to disguise his or her identity. On both sides of each page, sufficient margin was allowed to add analytical remarks.

Audio recordings were used to validate each transcript. In several instances, the recordings were unclear; therefore, the participants were contacted again and requested to clarify their statements.

### 2.5. Analysis

IPA consists of the following steps:

1) **Multiple readings and note-taking.**

This phase needs reading and listening to available transcripts and audio recordings. This makes it simpler for the researcher to engage with the data and recall the interview’s context. At this moment, the researcher simultaneously notes the highlighted observations, reflections, and emotional reactions.

2) **Converting notes into developing themes**

Now, the focus shifts from transcripts to researcher notes. This phase seeks to transform notes into developing topics. The development of a concise language that references psychological concepts. In this step, which contains the hermeneutic circle, the portion, and the whole are understood in conjunction. In this step, the transcript is therefore evaluated as a whole.

3) **Seeking linkages and thematic clusters**

In the last phase, relationships between emerging concepts are studied, they are grouped based on
conceptual similarity, and each cluster is assigned a more descriptive label. Several topics are regularly eliminated because they do not align with freshly developing themes or lack sufficient supporting evidence. The finalized list contains a variety of crucial and minor subjects.

3. Quality and validity considerations in qualitative research

The guidelines established by Yardley\textsuperscript{24} for evaluating qualitative research were implemented in the present study. Smith\textsuperscript{25} presents four implementation principles for these guidelines: sensitivity to context, dedication and rigor, transparency and coherence, and impact and significance. Researchers have made every effort to adhere to these recommendations.

4. Result

The present study aimed to understand the lived experiences of Indian cancer patients who abandoned treatment using interpretative phenomenological analysis. Four superordinate themes were identified, encapsulating the experience of cancer patients. (i) ‘Lack of knowledge about cancer’ dealt with the knowledge and perceptions patients had about their cancer. (ii) ‘Hopelessness with oneself and God.’ (iii) ‘Distress caused by numerous cancer-related issues’ captured the challenges faced by cancer patients. Finally, the last superordinate theme, (iv) ‘Patient dissatisfaction with physicians and treatment’ dealt with cancer patients’ interaction with and expectations from their oncologists as well as the medical staff. These four superordinate themes served as a determining factor for treatment abandonment among cancer patients.

(i) Lack of knowledge about cancer

This superordinate theme illustrates the participant’s lack of awareness about the symptoms of cancer. It also includes the beliefs and perceptions patients hold about cancer. This superordinate theme is comprised of two subthemes: confusion about symptoms and cancer is incurable. The subtheme confusion about symptoms suggested that the patients lacked clarity about the illness. The following extract is of a patient who thought that her oral cancer was a simple mouth ulcer.

\textit{I thought it was a mouth ulcer, but it came out to be such a dangerous illness… I got tested. The doctor said, this is not what you are thinking, it is cancer. … Firstly, it began with my right ear. Maybe this is why problems in my mouth began. I could hear a whirring sound in my ears. God has made this my destiny. (O1)}

The initial symptoms, such as mouth ulcers and whirring sounds, were misinterpreted as causes of cancer. The comment, “I thought it is a mouth ulcer,” signifies that in oral cancer, the initial symptom, which is an ulcer, is never associated with cancer. When patients suffer from prolonged ulcers or have difficulty eating, they consult the physician.

While with breast cancer, even a tiny lump is alarming for the patients. The following extract is of a breast cancer patient who was unclear whether the lumps in her breast were fibroids or tumors.

\textit{When winter came, I got to know that it was a cyst. I don’t know whether it is an accumulation of tissues or a tumor. It does not move. Seems like it is everywhere. (B1)}

Patients constantly get inputs from their bodies, and they are attentive to the minute changes in their bodies, which could be interpreted through the comment, “Seems like it is everywhere”. It suggests that the patients constantly check their bodies to make sense of the changes. The positive change, such as alleviation in the symptoms, decreases the magnitude of stress, while the negative change, such as deterioration in health, increases the magnitude of distress. Lack of clarity about the symptoms has a cumulative effect on the distress level of patients.

One patient suffering from stage II prostate cancer thought that he had renal calculi, while others thought it was some kind of sexual disorder. The symptoms of prostate cancer, such as frequent urination, were mistaken as diabetes and renal disease in the first patient. So he went to a urologist, who referred him to an oncologist.

\textit{I used to urinate four to five times during the night. I thought I had diabetes, but the sugar level was normal. Then I thought there was some problem with my kidney, so I went to a Urologist. He referred me to another doctor (oncologist). (P1)}

The other stage II prostate cancer patient got afraid when he saw blood in his semen.

\textit{At first, I couldn’t understand what was going on. I was bewildered. I knew about stomach, breast, and oral cancer but not about prostate cancer. I thought I was suffering from some sexual disorder. I did not talk about blood to anyone or my wife. (P2)}
The comment, “I couldn’t understand what was going on,” signifies the shock the patient experienced after seeing the blood in his semen. This unusual symptom is associated with a sexual disorder, which is considered shameful in Indian society. The patient was so ashamed and distressed that he did not tell his wife about the blood. He also reported that he had no idea that one can suffer from prostate cancer too; he only knew about stomach, breast, and oral cancer.

Participants viewed that their cancer was incurable. They believed that even if it is cured, it will come back.

The illness will remain with me my whole life. . . . I have stopped overeating tobacco but eat a little bit. (O1)

This is an extract from O1, whose oncologist assured her that her cancer is in its early stages and curable, yet she continues to consume tobacco. After receiving treatment, the condition persisted since cancer takes time to recover. The length of time required to alleviate cancer symptoms and chemotherapy adverse effects plays a determining role in the perception of cancer’s timeline. The longer this duration, the more negatively the cancer timeline will be perceived. The statement “the illness will remain with me my whole life” demonstrates that cancer is incurable because, rather than experiencing symptom relief as a result of treatment, patients experience additional symptoms due to treatment side effects. This led to the belief that cancer cannot be cured.

I don’t think it will heal. Once cancer enters your body, it never leaves. (B1)

Similarly, for patient B1, the belief that “once cancer enters your body, it never leaves” was a result of the absence of symptomatic relief.

(ii) Hopelessness with oneself and God

The current superordinate theme demonstrates participants’ hopelessness with themselves as well as the supreme being. Patients during the initial stages of therapy were hopeful that their cancer would be cured, but as they moved along the trajectory and the symptoms worsened, they started to lose hope. The comment, “only waiting for death” (P2), signifies that the ray of hope has been diminished.

Now, I am only waiting for the death. (P2)

God made me sick. He made this my destiny. (O1)

What wrong did I do to God that this happened to me? I never thought ill of anybody (sobs). . . . Why did this happen to me? Everyone has to die one day, but at an appropriate age and in an appropriate manner, not in such a spiteful way. (P1)

The extract of patients O1 and P1 unveils that the causal attribution of cancer is towards the divine being, which was “God made me sick” and “What wrong did I do to God.” Although patient O1 used to consume tobacco, the reason for her cancer, as per her belief, is God, the supreme power has afflicted her as well as patient P1 with cancer. P1 believed that he had not committed any wrongdoings against God or other people, so he questioned why God had punished him with cancer.

I was getting treatment thinking that it was my job, but healing only resides in the hands of God, and he did not do anything. (B1)

Patients never expected that they would suffer from cancer, and so they blamed God for their illness. Even the idea of recovery was attributed to the supreme being. The extract of the patient (B1) suggests that although the patient was undergoing treatment, she had a strong belief that she would only recover when God made her recover. But when the symptoms did not alleviate, she started to believe that God did not want her to recover.

(iii) Distress caused by numerous cancer-related issues

Distress is a multifaceted, painful emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may impair one’s capacity to cope effectively with cancer, its physical symptoms, and therapy. There is no single patient who does not experience distress; in reality, the diagnosis of cancer and distress come hand in hand. The magnitude of distress may range from normal feelings of vulnerability to a clinical state such as depression, depending upon the coping resources of the individual. In the present investigation, patients reported several sources of distress, such as stigma related to cancer, distress at the time of diagnosis, issues related to physical and sexual problems, and lack of social support.

(a) Stigma related to cancer

The subtheme informs about how cancer in India is still stigmatized and perceived as something for the lower caste.
When I told my mother, she warned me not to tell anyone and asked me to apply homemade ointment. But when I started my treatment, people in the village started strangely staring at me as if I belonged to some low caste. I am of a higher caste. (B1)

The above extract is of an unmarried girl (suffering from breast cancer) whose mother forbids her from disclosing her symptoms to family and friends. Instead of taking her to the Doctor, she asked her to apply homemade ointment. This reveals that if a girl is unmarried and has cancer, it will be difficult to marry her off even after she has completely recovered. The comment, “People started strangely staring at me,” also reflects the misconceptions people in rural India hold about cancer. The ‘strange’ look being discussed indicates that casteism is still prevalent in Indian society. Another comment, “I am of a higher caste,” signifies that cancer among people belonging to rural India is perceived as a disease of lower caste and not meant for individuals of upper caste.

Then I covered myself with a gamchha (a cotton cloth used by men in India to protect oneself from heat and sunlight) and went to a Hakeem (local practitioner). Hakeem was known for the successful treatment of infertility. (P2)

The extract of prostate cancer patient (P2) illustrates that not only females but male cancer patients also become the victim of social stigma. When the patient saw blood in his semen, he thought he was suffering from some kind of sexual disorder. He went to a local practitioner (Hakeem), known for successfully treating infertility. The comment “I covered myself with gamchha” signifies that the patient wears a veil so no one can recognize him. It also reflects the shame one experiences while suffering from a sexual disorder. In rural India, it is considered disgraceful for men to visit infertility clinics.

(b) Distress during diagnosis is common among cancer patients. It is mainly reflected in the fear experienced by patients. When patients heard about the diagnosis for the first time, it came as a shock for them.

I used to feel very anxious. Used to dream about my cremation. (P2)

P2’s remark that he “used to dream about my cremation” exemplifies the dread of death that cancer patients experience.

When I got to know it was cancer, a chill ran down my spine. I couldn’t sleep for many nights...used to feel perplexed and restless. (P1)

The comment of P1, “I couldn’t sleep for many nights,” also signals the extreme fear, anxiety, and worry one goes through when diagnosed with cancer.

When I first found the lump (in the breast), for two or three days, everything looked so confusing. Constantly, I used to think about what people would say about me. (B1)

When the doctor said I have this (cancer), I got scared; you know how negative the perception of this disease is. (O1)

Female patients (B1 and O1) did not say the word ‘cancer’ even once in all the interview sessions. To refer to cancer, both used words like ‘this’ and ‘lump.’ This indicates the level of fear associated with cancer. Despite all cancer patients being in the initial stages of cancer, they dreaded it a lot. It is because of a lack of knowledge about cancer and the extremely negative perceptions associated with it.

(c) There were also issues related to sexual problems the patients were experiencing.

I got chemotherapy done, and it shattered my whole body. Now even walking is difficult. ...I do not remember when was the last time I slept (sex) with my wife. Sometimes, I pity my wife; she also suffers because of me. She never says, but I am always scared she will leave me. (P1)

The subtheme issues related to sexual problems revolve around the physical closeness with the spouse, which gradually diminishes as a result of cancer and its treatment. The comment in the first extract, “What if she leaves me,” signifies the distress and fear that the prostate cancer patient was experiencing. He was afraid of her leaving him as he could not form an intimate relationship with her and satisfy her. He was also skeptical about how long his wife would take care of him and who would look after him if she left as he could not even walk on his own. Also, he realized and was worried that his primary caretaker, who happens to be his wife, is also facing problems due to his cancer.

It’s only five years since I got married. My wife is just 25. I cannot give what my wife deserves; we have even started sleeping in different rooms. (P2)
The second extract also represents the similar experience of prostate cancer patients. The comment “my wife is just 25 and unable to give what my wife deserves” represents the distress the patient experiences when they are unable to perform their role of being a husband. He is distressed that he is unable to satisfy the sexual needs of his young wife. “We have even started to sleep in different rooms” indicates a perception of distance in the relationship that has built up.

My husband’s behavior towards me has changed; he says nothing, but we women can feel it. (O1)

The third extract is of an oral cancer patient who can sense a change in her husband’s behavior. The comment “he doesn’t say anything, but we women can feel it” also indicates that their relationship has been affected negatively due to cancer.

(d) Lack of social support

When expectations are not met, frustration and disappointment can result. These emotions can contribute to increased distress, as individuals may miscalculate the resources necessary to cope with the situation.

During the treatment, my elder brother did not help even a bit. Because of him, my family was alone. My elder brother never even visited Allahabad. My children lived alone. He never came asking how you all are and how you are managing. (P1)

When I went for treatment, everyone in my family said first to arrange for a huge amount of money before they proceeded for treatment. This disease is incurable. No one said that if you need some money, I will help you. (O2)

In a collectivistic society like India, when someone suffers from a chronic illness like cancer, it is expected that close as well as distant family members will come forward to provide tangible support. However, when patients fail to receive this support, they expect it to result in increased distress.

(iv) Patient dissatisfaction with physician and treatment

When an individual suffers from cancer, a relationship with medical staff becomes part and parcel of life. Hence, patients may feel dissatisfied with their oncologist and their treatment.

First, I consulted another doctor, but he never used to listen to me. They just scolded me for asking questions and never gave me time. He used to be in a hurry during consultations. He must be examining around 200 to 250 patients each day. (P2)

After the first round of chemotherapy, when I called Dr Sarita (pseudo name) to tell her about my vomiting, she very rudely said, if you are facing so many issues, then get yourself admitted to the hospital. She spoke to me so badly. (B1)

I changed two doctors. My first doctor (quack) seemed like he did not know anything. He never used to say much and used to give medicines in a packet. Then I consulted another doctor, and he always used to be angry. Whenever I used to ask something, he didn’t even care to reply. I left him as well. Now, there is no money also to go and give to such people. (O2)

The above extracts illustrate the discrepancy between the needs of the patients and the supplies provided by the environment (physician). The comments “scolded me for asking questions,” “never gave me time,” and “used to be in a hurry” suggest the psychological needs of the patients. Cancer patients want their oncologist to be empathetic, answer their queries related to the disease, and give them ample time. The comment of another patient, “She spoke to me so badly,” signifies patients’ dissatisfaction with their oncologist. The patient expected that when she talked about the side effects of chemotherapy (vomiting, dizziness, fatigue), the doctor would understand and respond in a caring manner and give some more medicine to nullify this effect. Instead, the doctor insensitively asked her to get admitted to the hospital. It is not that oncologists in India are indifferent, but the workload is generously high, as the comment “he must be examining around 200 to 250 patients each day” suggests.

Within 15 days only, I was diagnosed with cancer. I was terrified. They said, look, this is in the initial stage; it will heal. I said I had come from a faraway place. I want to go back home. He said I am understanding. Once the other reports (test results) come, you can go. (O1)

The above extract illustrates a different patient experience. The comment, “Look, this is in the initial stage; it will heal,” illustrates how the behavior of the oncologist impacts the level of distress the patient experiences. The comment, “I want to go back home. He said I am understanding. Once the other reports (test results) come, you can go,” unveils a significant issue. Whatever the oncologist says after the diagnosis of cancer plays an important role in lowering the
magnitude of distress experienced. It also paves the path for the treatment.

I believe the tissues have collected all over my breast. So, should I get the whole breast removed? No one can estimate how far it has reached. What if they take out the whole of my breast. …… When I consulted, 2 km away from Dhanbad, he said it was cancer. Another doctor said it is not cancer; it is some kind of fibroid. Finally, one doctor said it is cancer, but it can be cured. (B1)

The above transcript shows how differences of opinions in medical diagnosis can result in negative perceptions about the disease, its treatment, and the physician. The comment “he said it is cancer. Another doctor said it is not cancer, it is some kind of fibroid. Finally, one doctor said it is cancer, but it can be cured” illustrates how patients in rural India go from one physician to another because their symptoms are not alleviating and because they are not satisfied with the physician.

Someone sent me to another doctor (quack). I got medicines from there, but there was no relief. … after that, I began homeopathy treatment for one year, but it also did not work. I left the treatment. How much treatment should I undergo? Doing it for so many years. Now I stay like this only. The pain increases during winter. But what to do? There is no cure. (O1)

The above extract shows the harsh reality of the Indian Healthcare system, the ‘quacks’. When patients first visit a Quack (an impostor or unqualified individual who has no medical knowledge or skill but runs a private clinic). This individual is incapable of providing treatment, so, the treatment he provides does not relieve the patient. In this course of time, the patient’s disease progresses, and patients start to form negative perceptions about the disease, consequently leading to negative perceptions of the treatment as well as dissatisfaction with the treatment.

Chemotherapy deteriorates the whole body. After the first chemotherapy, I decided no matter what, I would not go for another round (of chemotherapy). I will get the surgery done but won’t take the chemo. But after the surgery, again, I had to undergo three rounds of chemotherapy. And after that, I couldn’t take it anymore. …… After the first chemo. I stopped the treatment; I became very sick. When it is clear that cancer has spread, then what is the need to undergo more rounds of chemotherapy and get sicker? (P2)

The above extract illustrates the dark side of chemotherapy. It leads to an approach-avoidance conflict where the patients need to undergo chemotherapy to recover, but simultaneously, they also have to deal with the extreme side effects of it. The patient starts to associate vomiting, fatigue, and lack of energy due to chemotherapy with the worsening of their cancer. The comment “when it is clear that the cancer has spread” is of the patient who was diagnosed with stage 2 oral cancer, and her doctor even assured her that the survival chances were high, then too she abandoned the treatment. Because of the negative consequences of chemotherapy, the patient started to assume that the cancer had spread.

People say that if the blade touches cancer, it spreads more quickly, so there is no use for surgery. (B1)

Then, the misconceptions about treatment also lead to treatment abandonment. The comment “people say that if the blade touches the cancer, then it spreads more quickly” represents the misconceptions associated with cancer and its treatment. Despite the doctor’s suggestion, the patient did not undergo surgery and discontinued therapy. The views about treatment patients hold are determined by the people around the patient. As Leventhal suggested, beliefs about the disease are culturally determined in the same way beliefs about the treatment are also culturally determined.

5. Discussion

The present study aimed to comprehend the lived experience of Indian cancer patients who abandon treatment. The interpretative phenomenological analysis resulted in four superordinate themes: (i) Lack of knowledge about cancer, (ii) Hopelessness with oneself and God, (iii) Distress caused by numerous cancer-related issues, and (iv) Patient dissatisfaction with physicians and treatment. It can be interpreted that these factors were an essential factor for deciding to discontinue treatment.

Despite the government’s initiative to increase cancer awareness, many people in India are still unaware of the disease’s signs and symptoms. Detection is the first step to any successful treatment. As patients held various misconceptions about cancer, they themselves took time to reach out for help. Tiwari, Kishore, and Tiwari reported that after observing their symptoms for the first time, 57% of patients either ignored them (56%), tried a home remedy (26%), or consulted a local practitioner such
as a Hakeem, Moulvi, Pundit, or Spiritual Healer (18%).

Even when patients (in the present study) consulted the physician, in all cases, the first physician was either a quack or a local practitioner. This illness behavior increases the recovery timeline, and when symptoms do not get alleviated, the negative perceptions about the treatment as well as the disease start to sync in. Longer illness duration has been linked to treatment abandonment.

These negative illness perceptions or lack of knowledge about cancer have also been linked to hopelessness. Even if patients were diagnosed with cancer at an early, treatable stage, they lacked hope. Lack of knowledge about cancer led to hopelessness and distress in the present sample.

Patients felt distressed as the doctor-to-patient ratio is usually high in India. Hence, oncologists cannot address their patients’ concerns. In particular, their counseling and communication skills came under scrutiny. Patients reported wanting to discuss their issues with the oncologist, but they were reprimanded for doing so. Instead of decreasing, the level of distress among the patients increased because of the communication gap. Therefore, patients discontinued treatment when they were unable to comprehend what cancer is, the disease’s prognosis, and how long the treatment could last.

How patients interpret their cancer impacts their disease management. When perceptions of cancer are highly negative, treatment and recovery become bleak for the patient. Also, when disease information is imprecise or insufficient, it leads to high levels of anxiety and dissatisfaction with both the healthcare professional and the treatment.

Nonadherence among Indian cancer patients has been found to be associated with factors like age, gender, stage of cancer, toxicity due to treatment, and distance from home to the hospital. Treatment abandonment has been linked to high-cost private cancer care, old age, marriage, earlier age of illness onset, longer illness duration; less supervision for medication at home, continued symptomatology, negative attitude toward medications, poorer insight; poorer adherence; and poorer therapeutic alliance, and advanced cancer stage. None of the patients in the present study were old. The age ranged from 19 to 40 years. Both male and female patients were included in the study and were in either stage I or stage II of cancer, which was treatable. Thus, it can be interpreted that patient dissatisfaction, which was common among these patients, could be the reason for treatment abandonment. This dissatisfaction with the physician and treatment was related to a lack of knowledge about the disease, negative perceptions about the disease, and treatment and distress.

**Limitations of the study:** The sample size in the present study was small and limited to the rural background of the country. The study highlighted the perspectives of a homogenous group. Including participants from urban backgrounds may unveil various other causal factors related to treatment abandonment. Since the patients were familiar with each other as they went for chemotherapy in the same hospital, the decision to abandon the treatment of one participant may have reinforced the other participant. Further researches are required to verify the results.

**Implication of the study:** For healthcare professionals, it is crucial to understand the importance of patient dissatisfaction, as a dissatisfied patient may abandon treatment. For the Ministry of Health, in programs such as the National Programme for Prevention & Control of Cancer, Diabetes, Cardiovascular Diseases & Stroke (NPCDCS), there is a need to incorporate awareness campaigns about factual information regarding cancer and its treatment. Also, patients need to understand the stress faced by oncologists providing their services in Indian hospitals. Furthermore, a need for counselors or psycho-oncologists in cancer care units cannot be neglected owing to the threefold increase in cancer burden in 2025. Though the phenomenon of patient
dissatisfaction has been recognized at an international forum such as the WHO, it has never been anticipated to be a significant cause of treatment abandonment among cancer patients.

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