



THE PSYCHOLOGICAL TRAJECTORY OF CANCER PATIENTS IN INDIA: A PHENOMENOLOGICAL STUDY

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Abstract

Introduction: An individual's cancer trajectory has been described as a 'living-dying' experience in which s/he confronts the awful incompatibilities between life and death and seeks to keep control and normalize daily activities. Perceptions of the duration, course, and impact of a disease affect the recovery and management of the disease.

Aim: The purpose of this study was to explore the psychological trajectory of cancer patients in India interpretive phenomenological analysis (IPA).

Method and Materials: Eleven participants ranging in age from 19 to 80 years old (five male and six female) were enrolled in the study. A semi-structured interview schedule was used to acquire the data.

Results: The IPA produced four superordinate and eight subordinate themes. Encounter with medical care (Empathy and communication with doctor and Opinions about treatment), After-effects of sickness (Dissatisfaction with body and Emotions of uncertainty-Democles syndrome), and finally, Hopelessness/Hopefulness. Based on these superordinate and subthemes, the psychological trajectory of cancer patients in India was split into three phases: the initial, shock and transition phase, the second, encounter, sustenance and recovery phase, and the third, survivorship phase.

Implication of the study: Patients, physicians, and lawmakers must acknowledge that the psychological requirements of cancer patients cannot be ignored, as it not only affects their quality of life and survival, but also the economic burden arising from cancer occurrence and recurrence.

Keywords: cancer, psychological trajectory, interpretative phenomenological analysis

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1. Introduction

An individual when diagnosed with cancer is a naïve in that situation. The diagnosis of cancer poses a danger to one's overall sense of security and order in life. A cancer diagnosis results in a bizarre interplay of concerns, such as coping with physical symptoms and treatment, as well as fear and uncertainty regarding the condition. A cancer diagnosis can cause significant disruption in an individual's life. It is not surprising that cancer patients may experience grief, concern, demoralization, and/or anger, given the rapid, widespread, and demanding character of the disease. An individual's cancer trajectory has been described as a 'living-dying' experience in which s/he confronts the terrible incompatibilities of life and death, and consequently attempts to maintain control and normalise daily activities.^[1] Sickness is a subjective experience, and each individual has a unique experience. So, the response to sickness differs from person to person.^[2] Perceptions of the disease's length, course, and effects influence its treatment and management.^[3] How individuals experience cancer, as well as how they define and perceive it, plays a determining role in cancer adjustment and treatment.^[4] Consequently, academics have begun to focus on comprehending the significance that cancer patients give to their illness. According to studies, patients' perceptions of cancer have a vital role in shaping their discomfort and coping strategies^[5]. Medical (clinical course of the disease, including pain and suffering), psychological (level of disruption of life goals and the ability to modify life plans), and social factors (such as social support) also influence the level of distress a cancer patient may experience^[6], which in turn influences their ability to cope. Hence, in order to comprehend how people cope with cancer, it will be researched within a framework of self-regulation^[7]. The paradigm posits that people have common sense ideas about diseases, and that these beliefs determine how they deal with the sickness. Illness cognition refers to these commonsense assumptions or an individual's understanding of their sickness.

The aim of this research was to explore the psychological trajectory of cancer patients in India using interpretive phenomenological analysis.

The objective of interpretive phenomenological analysis (IPA) is to investigate in depth how people make sense of their personal and social worlds^[8]. As Leventhal and colleagues^[7] stated that how people make sense of their sickness influences how they cope with it, the application of IPA appeared to provide an answer to the topic of how cancer patients make sense of their experience and what its important components are. Moreover, the self-regulation framework is founded on phenomenological research^[9], and IPA implies that individuals are "self-interpreting creatures".^[10] Leventhal, Benyamini, Brownlee, Diefenbach, Leventhal, Patrick Miller and Robitaille^[11] also proposed that illness cognitions are culturally dictated; thus, it was necessary to conduct research in this area in order to comprehend the Indian cultural aspects that play a part in illness cognitions of cancer patients.

2. Method

Ethics: Ethical approval was sorted from Institutional Ethics Review Board (IERB) of University of Allahabad.

Sample

Participants were recruited for the study using the snowball sampling approach. The study included 11 individuals ranging in age from 19 to 80 years old (five male and six female).

Inclusion criteria of the sample

The participants were selected on the basis of the following criteria.

- 1) The patients' age must be at least 18 years old.
- 2) He or she must understand the diagnosis.
- 3) No physical or psychological comorbidity should exist.
- 4) Patients must have had therapy at the cancer hospital or be receiving treatment there.

Table No. 1 – Table showing demographic characteristics of the sample (N=11)

S. No.	Age	Gender	Background	Socio-economic status	Site of Cancer	Stage of Cancer	Treatment Modality	Phase of Treatment
1.	65	Female	Rural	Low	Tongue	I	Surgery	Follow up
2.	46	Female	Rural	Low	Cervix	I	Chemotherapy + Radiation Therapy	Follow up

3.	42	Female	Urban	Middle	Breast	I	Surgery + Chemotherapy + Radiation Therapy	Survivor
4.	53	Female	Urban	Middle	Tongue	I	Surgery + Radiation Therapy	Survivor
5.	35	Female	Urban	Middle	Breast	I	Surgery + Radiation Therapy	Survivor
6.	37	Female	Urban	Middle	Breast	II	Chemotherapy	3rd phase of Chemotherapy
7.	38	Male	Rural	Low	Oral	I	Surgery + Radiation Therapy	Follow-up
8.	41	Male	Rural	Low	Mouth	II	Surgery + Chemotherapy + Radiation Therapy	Follow-up
9.	73	Male	Urban	Low	Stomach	II	Chemotherapy	3rd phase of Chemotherapy
10.	62	Male	Urban	Middle	Tongue	I	Surgery	Follow-up
11.	50	Male	Urban	Middle	Oral	I	Chemotherapy	1st phase of Chemotherapy

Interview Schedule

Normally, IPA studies require an in-depth semi-structured interview. [12] Hence, a semi-structured interview schedule was devised. The interview schedule consisted of two segments, the first of which covered demographic information as well as disease and treatment information. The second segment had questions about the experience of the illness.

Procedure

The participants were contacted by phone in order to schedule the interview. At the initial encounter, the participants were briefed on the purpose of the study and rapport was created. They were informed that the interview would be audio recorded, but that it would not be shared with anybody and would be used solely for research purposes. The interview sessions ranged from 45 minutes to 1 hour and 15 minutes. Three to five sessions were necessary per interview. Each interview was then transcribed for the analysis.

Data Analysis

Pietkiewicz and Smith's [13] Interpretative Phenomenological Analysis (IPA) was utilised to analyze the data. It is based 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 meaning to make it more comprehensible. The participants interpret their reality before the researcher attempts to make sense of that interpretation. [14] The steps involved in IPA are as follows:

- 1) Multiple reading and making notes
- 2) Transforming notes into emergent themes
- 3) Seeking relationships and clustering themes

3. Result

The super-ordinate themes and the subthemes are summarized in the table below.

Table No 2 - Master Table showing the super-ordinate themes and their constituent subtheme

Super-ordinate theme	Subtheme
Personal encounter with cancer	Illness cognition
	Distress
	Coping
Encounter with medical care	Empathy and communication with doctor
	Views about treatment
After effects of illness	Dissatisfaction with body
	Feelings of uncertainty-Democle's syndrome
Hopelessness/Hopefulness	Oscillating between hopelessness and hopefulness

The IPA resulted in four superordinate and eight subthemes. The psychological trajectory of cancer patients can be divided into three phases; **the initial or the shock and transition phase** in which the individual takes the role of an ill person from being a healthy person. The **second phase or the encounter, sustenance and recovery phase** is the phase where individual comes in contact with the disease as well as the medical care. The individual sustains the physical and psychological injury and struggles to recover from cancer. It includes the superordinate themes, personal encounter with cancer and encounter with medical care. **The final phase or the survivorship phase**, here individual deals with after effects of cancer.

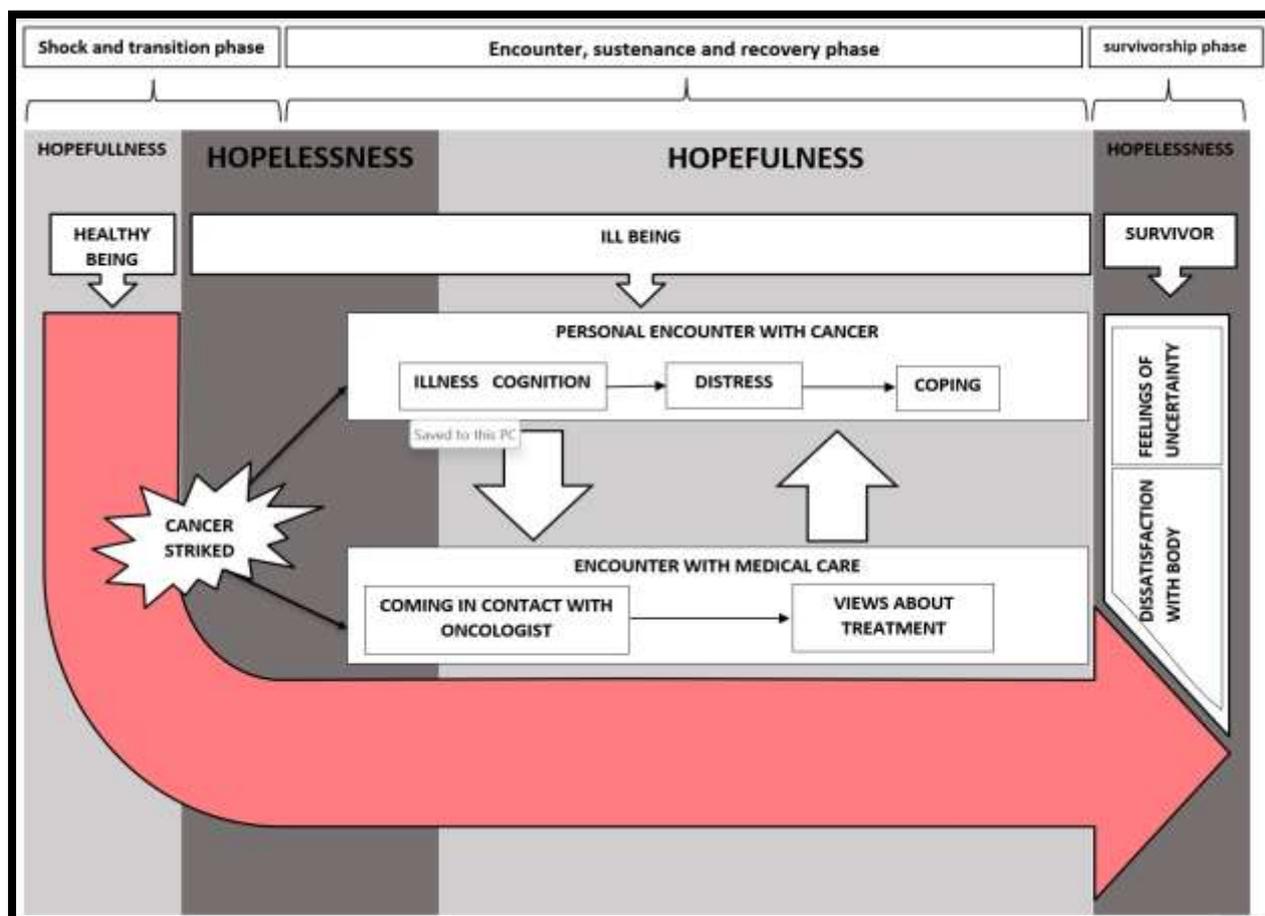


Figure 1: Figure showing the psychology trajectory of cancer patients

The initial or the shock and transition phase
Patients in this phase can be considered to be in the "shock phase" when they are healthy and hopeful before they are informed that they have cancer. This is because the news comes as a complete shock to

them. The individual then needs to shift his role in the relationship from that of an independent carer to that of a dependent patient.

The second phase or the encounter, sustenance

and recovery phase

When patients are provided with a label to their illness, this results in the process of making sense of that illness. The implicit common-sense belief a disease is known as illness cognition (Leventhal and).

Illness Cognition

The comprehension of cancer aided patients in dealing with and managing cancer. The illness cognition spread across five dimensions, identity, cause, consequence, timeline and control.

Despite being a chronic disease, cancer was associated with a shorter timeline. A shorter timetable does not indicate that cancer will soon be cured; rather, it has reduced the participants' lives. It will stay with them for the rest of their lives.

"It is a lifelong disease, God has made us sick. This is a curse, it will go with life."

Patients with cancer in India ascribed their sickness to spiritual beliefs. The attributing of events to God's will is prevalent in Hindu culture. This attribute is not restricted to stoic resignation. Attributing something to God's will is sometimes followed by rage.

"What did I do to God that this happened to us, till date I have never wished bad for anyone, never done anything bad to anyone, (sobs) why did this happen to me. I have become so old that I had to die, but it is not so terrible"

Distress

How patients understand their illness determines their perception of stress. Cancer touched practically every aspect of the participants' lives. Participants reported physical problems, dread, anxiety, a financial crisis, and interpersonal difficulties.

"When I came to know that I have cancer, at that time a chill ran down my spine, I did not sleep for many nights...there was a lot of confusion and restlessness"

Cancer has conventionally been linked to death. As a result of their dread of disease, participants avoided taking the name cancer.

"When the doctor said that I have this (cancer), I was scared, you know how bad the name of the disease is."

In a crisis-stricken collectivist society, individuals have a tendency to seek support from those who have been close to them for a very long period. Participants indicated a lack of social support throughout their crises, which aggravated their distress.

"My elder brother did not give any support during my illness. Because of which our family was left alone in the village. My brother never even came to see me in Allahabad (hospital). Our children lived alone, never even went to ask about them."

Coping

Along the trajectory, participants were required to confront the problems posed by cancer on an ongoing basis. Participants in the present sample did not limit themselves to a single coping strategy; rather, they adopted a variety of coping methods at different stages of the disease. Participants in the present sample utilized denial, acceptance, active coping, information searching, seeking social support, religious coping, and karmaphala.

For the majority of participants, acknowledging their cancer diagnosis was the first step towards overcoming its threat.

"If I have to die, I will die, and if I have to live, I will live"

For some participants, searching for information about the condition facilitated social comparison. They noted that the patients whose conditions were better than those of the participants inspired them to continue the treatment. That gave them hope that they, too, may overcome cancer and regain their health. Whereas comparison with patients whose health was worse than that of the participants elicited emotions of satisfaction, i.e., they believed they were in a better position than others.

"Look at him (pointing towards another patient) he has been intubated, he is neither able to eat nor drink, his wife pours juice from the tube. Everything was removed from his mouth during surgery, not even tongue is left, can't even speak. We are talking to you (smiles)"

Encounter with medical care

The diagnosis results in nearly daily contact with the medical staff. The healthcare team is integrated with the patient's life. In comparison to other chronic disease patients, cancer patients typically demand a great deal of attention from their doctors. They anticipate that their oncologists will spend extensive time with them and address their emotional and informational requirements. Individuals in the present sample shared comparable anticipations.

Empathy and communication with doctor

Individuals are affected by the manner in which and quantity of information is presented. Some individuals claimed that their oncologist does not reply to their questions and concerns.

“Earlier I used to go to another doctor, but he didn't listen to anything, just kept scolding me, didn't even give time, always in hurry. Must be seeing at least 200-250 patients daily.”

Some participants found their oncologist to be empathic, i.e., they realized that the patient was experiencing extreme stress, but others did not.

Views about treatment

The experience of initial chemotherapy is the groundwork for generally negative attitudes towards chemotherapy. Being the most dependable and effective alternative for cancer treatment, however, cancer patients typically do not abandon it.

“Believe me, chemo makes the body weak. After the first chemo, I decided not to undergo chemo no matter what happens. I will get the surgery done but will not get chemo. But after the operation, three more chemo had to be given.”

After effects of illness (survivorship)

Cancer leaves its victims with a scar. Individuals who were cancer survivors reported a variety of aftereffects. These included body dissatisfaction and feelings of uncertainty.

Dissatisfaction with body

It was not limited to appearance, but encompassed the body's overall functionality.

“...as if termites have penetrated deep into my body...I get tired of doing little work, get tired even if I organize the cloth, gets tired even if I swipe the floor.”

Feelings of uncertainty-Democles's syndrome

Participants who recovered from cancer said that there is hope for the future, but that it has become quite uncertain. Democles Syndrome refers to the persistent uncertainty surrounding cancer survival (National Research Council, 2006). In Greek mythology, it is stated that Democles was invited to the king's feast. A sword was suspended over his head by a single horsehair while he was forced to sit on a platform. Democles was pleased by the feast, but any attempt to reach the food would cause the blade to dislodge, resulting in his immediate death. According to cancer survivors, individuals continue to endure feelings of uncertainty and hesitate to make long-term plans. In addition, many noted that their lives have become increasingly uncertain.

“Now it seems anything can happen at any time. Don't know whether I will see tomorrow morning or not.”

Hopelessness/Hopefulness

Patients during their journey of cancer oscillated between hopelessness and hopefulness.

“Just get both the daughters married... Don't know what kind of house they will get... Now it is as if there is no hope from everything.”

4. Discussion

The aim of this research was to explore the psychological trajectory of cancer patients in India using interpretive phenomenological analysis. On the basis of above-mentioned superordinate and subthemes, the psychological journey of cancer patients in India was traced. The journey was divided into three phases namely; (i) the initial or the shock and transition phase, (ii) second phase or the encounter, sustenance and recovery phase and, (iii) The final phase or the survivorship phase.

In the encounter, sustenance and recovery phase, when diagnosed with cancer, patients describe two types of situations: one on the personal front and one on the medical front. Following receiving a cancer diagnosis, patients designate their internal bodily deviance as cancer, thereby activating the cancer-related prototypes, including the timeline, consequence, control, and cause. Patients' conceptions of cancer comprised of depictions of it as a fatal illness. They viewed cancer as a factor that has limited their life span. While their attribution of healing was postponed to personal control, therapeutic control, and most obviously supernatural power, their recovery was attributed to these factors. With these representations, the patient gained an understanding of their ailment.

Once a patient understood his or her illness, he or she experienced great anguish, including anxiety, fear, sadness, difficulties with social and physical functioning, pain, and weariness, among other symptoms. Everything the patients viewed was through the prism of cancer; their decisions regarding treatment, family, and employment were all made through the lens of a cancer patient. Hence, illness cognition generates multiple stressors, which in turn result in turn leads to coping.

This illness cognition, distress, and coping were not occurring in isolation, but were influenced by doctor-patient interaction and treatment perspectives. Communication with oncologist resulted in increased distress. When the symptom was not alleviated by treatment, additional discomfort ensued. When patients became more worried, they desired their physician's attention; however, due to the high doctor-patient ratio, the oncologist was unable to do so, which added to the patients' misery. The unhappiness with the physician and negative views about treatment resulted in aggravated patient's anxiety and despair.

As patients entered the survivorship phase after enduring this difficult circumstance, he or she suffered Democles Syndrome. they suffered apprehension, diminished future prospects, and a lack of long-term planning. Cancer survivors have described having difficulty achieving equilibrium, a sense of wholeness, and their life's purpose. ^[15]

The experience of being a survivor is dynamic, accompanied by psychosocial problems, life-related anxieties, and emotions of hopelessness. The patients in the current study oscillated between hopefulness and hopelessness. Before diagnosis, patients were filled with hope; after diagnosis, they felt hopeless; when they began treatment, a glimmer of hope returned; after treatment, when they became survivors, they once again began to feel hopeless because of feelings of uncertainty and fear of recurrence. According to qualitative investigations, patients experience fluctuating sensations of hope and despondency.^[16]

The distress experienced by cancer patients throughout their cancer journey, due to the unmet psychological needs, suppresses their immune system resulting in high mortality and low recovery rates. Patients, physicians, and policymakers must recognize that the psychological needs of cancer patients in India cannot be disregarded because it not only affects their quality of life and survival but also the economic burden resulting from cancer occurrence and recurrence.

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