

A PHENOMENOLOGICAL STUDY TO EXPLORE THE LIVED EXPERIENCE OF CANCER SURVIVORS TAKING TREATMENT AT PUDUCHERRY

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ABSTRACT:

Cancer is a leading cause of death worldwide on accounted for 7.4 million deaths around 13% of all deaths. The aim of the study is to explore the experiences and quality of life of the cancer patient. The study was conducted among the cancer survivors who are taking treatment at Regional Cancer Center, JIPMER at Puducherry. Research design used for this study is phenomenological design. This phenomenological study utilized a qualitative research methodology to explore the lived experiences of cancer survivors. Through purposive sampling technique, 30 cancer survivors were selected. Interview was conducted after consent. Socio-demographic data was collected with the use of a questionnaire, A semi structured face-to-face interviews with all 30 participants in a conducive environment. Interviews were conducted with an open- framework for two way communication and it was tape recorded. Researcher drew in eleven different phases of their life, from the themes developed from thematic analysis of the interview data. Researcher developed a theory known as "*Illness Experience Expectation Model*" based on the analysis of the verbatim of Cancer survivors.

KEYWORDS: Cancer survivors, lived experience, conducive environment ,IEE model,

INTRODUCTION:

Qualitative research is a form of social inquiry that focuses on the way people interpret and make sense of their experiences and the world in which they live. Qualitative research is an 'umbrella term', and a number of different approaches exist within the wider framework of this type of research. Most of these have the same aim to understand the social reality of individual, group and cultures. Qualitative approaches to explore the behaviour, perspectives, feelings and experiences of people and what lies at the core of their lives (Atkinson et al. 2007).

Phenomenological studies examine human experiences through the descriptions provided by the people involved. These experiences are called *lived experiences*. The goal of phenomenological studies is to describe the meaning that experiences hold for each subject. This type of research is used to study areas in which there is little knowledge (Donalek, 2004).

Cancer is a term used for diseases in which abnormal cells divide without control and are able to invade other tissues. Cancer cells can spread to other parts of the body through the blood and lymph systems.

Cancer is a potentially fatal disease caused mainly by environmental factors that mutate genes encoding critical cell-regulatory proteins. The resultant aberrant cell behaviour leads to expansive masses of abnormal cells that

destroy 3 surrounding normal tissue and can spread to vital organs resulting in disseminated disease, commonly a harbinger of imminent patient death.

The study was to explore the experiences and quality of life of the cancer patient who is on treatment and surgery. Cancer, one of the most dreaded diseases in the history of mankind, takes lives of more than 7 million patient's worldwide. People with cancer commonly experience a wide range of symptoms, including pain, anxiety and various types of physical and emotional distress. These symptoms span the course of the disease. Physical and psychological health is important target in patients under palliative care.

STATEMENT OF THE PROBLEM:

A phenomenological study to explore the lived experience of cancer survivors taking treatment at puducherry

OBJECTIVES:

- To explore the experience of cancer patients before diagnosis of cancer.
- To describe problems and challenges faced by the cancer patients after their status disclosure
- To identify the quality of life with proportion of treatment and surgery.
- To associate the quality of life with their demographic variables.

OPERATIONAL DEFINITIONS:

Explore: It refers to, inquire or investigate systematically the experiences of people living with cancer, using a face-to-face semi- structured interview method by using audiotape.

Lived experiences: it refers to thoughts and feelings about events and essence of people living with cancer.

People living with CANCER: the people suffering from cancer at Puducherry.

DELIMITATION:

The study is delimited to

1. The data collection period is only for 4 weeks.
2. The data will be collected from cancer patient taking treatment at Puducherry.
3. Sample consists of people diagnosed as cancer on treatment.

METHODOLOGY:

RESEARCH APPROACH:

The present study explored the lived experiences of Cancer survivors using face-to-face semi-structured interview

RESEARCH DESIGN:

Research design used for this study is phenomenological design

SETTING OF THE STUDY:

The study was conducted among the cancer survivors who were taking treatment at Regional Cancer Center, JIPMER at Puducherry.

POPULATION:

The population for the present study included the cancer survivors who are taking treatment at Puducherry.

SAMPLE:

In this study, samples consist of 30 cancer survivors on treatment at RCC, JIPMER

SAMPLE SIZE: 30

SAMPLING TECHNIQUE:

The sampling technique used for the study is purposive sampling technique.

Sample Criteria**Inclusion Criteria:**

1. Subjects who diagnosed as cancer on treatment.
2. Subjects who can understand Tamil or English.
3. Subjects who are willing to participate in the study.

Exclusion Criteria:

1. Subjects who are terminally ill patients.
2. Subjects who are not willing to participate.
3. Subjects who can't understand and reply answer to the questions.

TOOLS FOR RESEARCH:

The investigator used modified structured tool as per the standardized tool (Spitzer Quality of life index) for collecting data. The average time to taken to complete questionnaire was 25 minutes.

Section A: Demographic variables, it consists of age, sex, educational qualification, marital status, occupation, income, religion, type of cancer, stages of cancer, type of treatment, family history of cancer

Section B: A semi structured face-to-face interviews with all 30 participants in a conducive environment. Interviews were conducted with an open- framework which allowed for two way communication and it was tape recorded.

DATA COLLECTION PROCESS:

Researcher introduced herself and explains the study to the subjects. Interview was conducted after consent. Participant's socio-demographic data was collected with the use of a questionnaire. Researcher conducted a semi structured face-to-face interviews with all 30 participants in a conducive environment. Interviews were conducted with an open- framework which allowed for two way communication and it was tape recorded.

RESULTS AND DISCUSSION:-

When viewing the data, researcher drew lived experiences of cancer survivors in eleven different phases of their life, from the themes developed from thematic analysis of the interview data.

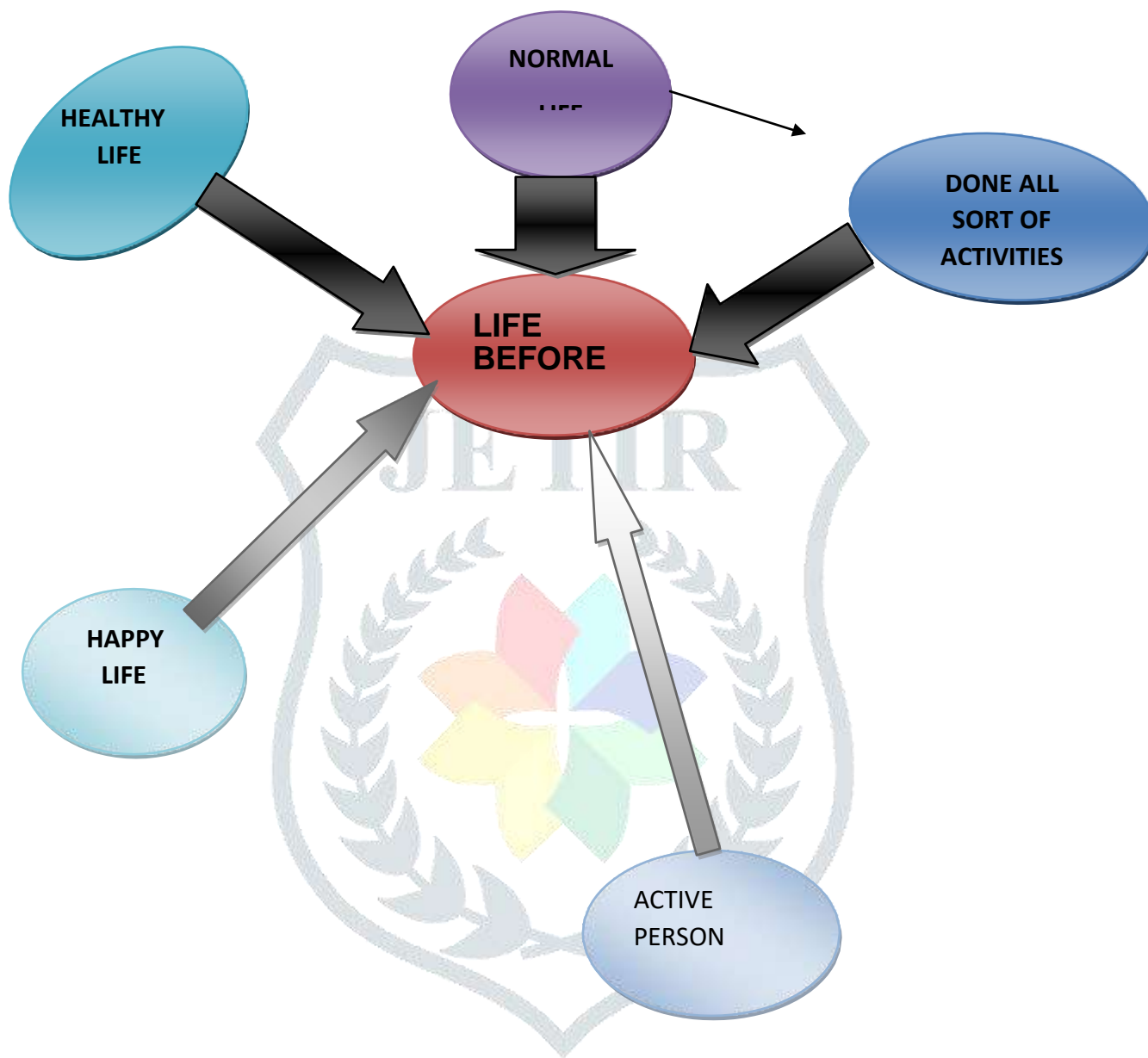
First objective of the study is to explore the experience of cancer patients, before diagnosis of cancer. The result highlighted that majority 96.6% of the 84 participants experienced they were lived a normal life before diagnosis of cancer and 50% of the participants experienced they were lost hope and strength, disappointment in life after diagnosis of cancer. 13.3 % of the participant's experience of slowly adopted their condition and the future is ambiguous.

Table 1: Frequency and Percentage of Categories

S. No	Categories	Frequency	Percentage
i)	Normal	29	96.6
ii)	Done all sort of activities	12	40
iii)	Healthy life	7	23.3
iv)	Happy life	6	20
v)	Active person	3	10

From the table and figure illustrated, it is understood that most of the participants were lived a normal life and done all sort of works.

FIGURE 1: STRUCTURE OF LIFE BEFORE DIAGNOSIS



The second objective of the study is to describe problems and challenges faced by the cancer patients after their status disclosure. The Seventh and eighth theme of the study was focused and describing this objective, in this seventh theme Inter and Intrapersonal relationship, 63.3% of them experienced self avoidance and 43.3% maintaining good relationship and few 16.6% reported bitter experience in relationship. Eighth theme of the study is mental health status, 60% of the participants expressed multiple stressors and 40% feels loneliness and least participants 10% reported that depressed mood.

Table 2;Frequency and percentage of categories

S. No	Categories	Frequency	Percentage
I	Lost hope	12	40
Ii	Frequent health problems	11	36.6
Iii	Lost strength	10	33.3
Iv	Disappointment in life	8	26.6
V	Struggling to accept	6	20
Vi	Slowly adopted the condition, Future is ambiguous	4	13.3
Vii	Left my job	2	6.6

From the table and figure illustrated, it is understood that most of the participants reported that they were lost their hope.

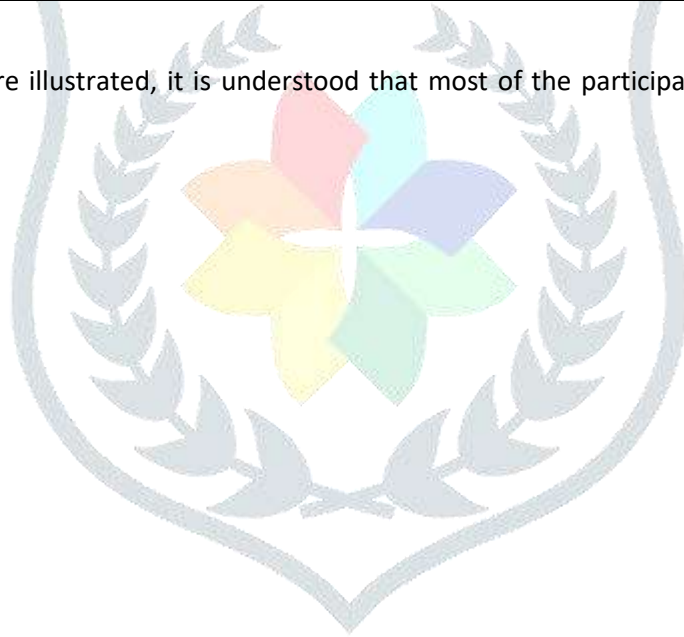
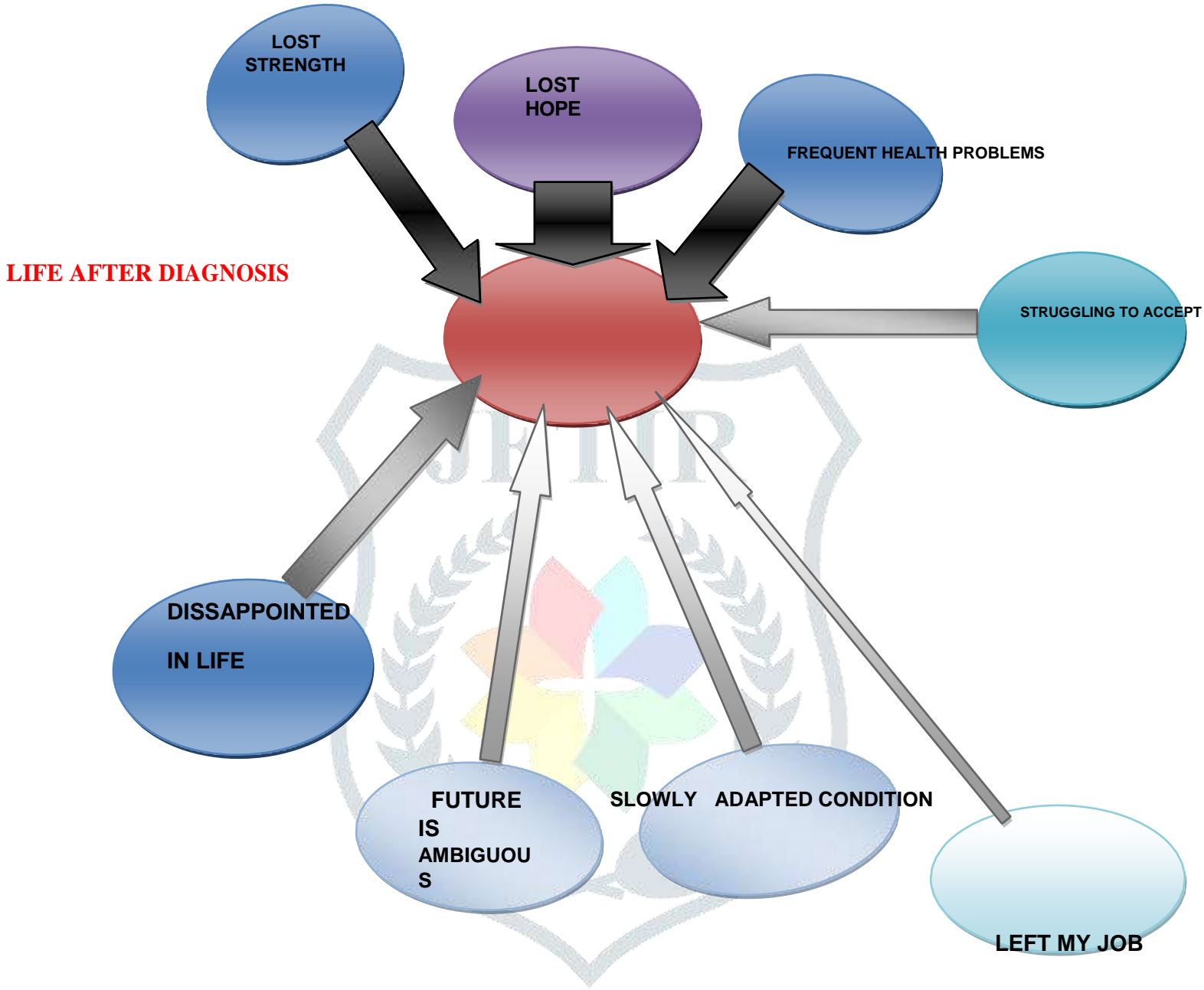


FIGURE 2: STRUCTURE OF LIFE AFTER DIAGNOSIS



The third objective of the study was to identify the quality of life with proportion of treatment and surgery. Based on the objective sixth theme is treatment experience and side effects, 83.3 % of the subjects were experienced of health condition improved and their side effects increased. 76.6% of the 86 participant's complaints of hair fall. Least 10% of the subject complaints of blurred vision, joint pain, oral ulcers, stomach pain, irregular periods.

Table 5: Frequency and Percentage of Categories

S. No	Categories	Frequency	Percentage
I	Health condition improved, Side effects increased	25	83.3
Ii	Hair fall	23	76.6
Iii	Tired, vomiting	22	73.3
Iv	Problem in food intake	20	66.6
V	Body pain	18	60
Vi	Asleep	17	56.6
Vii	Giddiness, changes in food habits	15	50
Viii	Believe treatment	14	46.6
Ix	Forced to removal of hair	12	40
X	Body image changes	11	36.6
xi	Weakness	10	33.3
xii	Distressed, indigestion, diarrhea	7	23.3
xiii	Skin changes, headache, hospitalized	5	16.6
xiv	Blurred vision, joint pain, oral ulcers, stomach pain, irregular periods	3	10
xv	Treatment delay	1	3.3

From the table and figure illustrated, it is understood that most of the participant's health condition improved and side effects increased.

DISCUSSION

The findings from this study follow the research questions and the findings,

Addressing four areas: (a) participants described a cancer diagnosis and complaints; (b) participants experienced care and relationship with others; (c) explore their treatment experiences and mental health status; (d) perception about cancer and future life.

In this study, researcher mainly focused on the living experience of the cancer survivors in different phases and also to understand the expectations of the survivors. Majority of cancer survivors bankrupt with emotions sharing their bitter experiences of their life. Researcher assimilated all the interview transcripts of survivors into a diagrammatic form. Hence the Illness Experience Expectation model is interconnected with the lived experience of cancer survivors and also focuses the nursing care of action.

CONCLUSION

This small scale phenomenological study provides some impending areas of concern from the cancer survivors. Lived experiences of cancer survivors reveal that illness after cancer, treatment experiences and expectation of life. In addition to this, it also explored the thrash about cancer survivors which undergo in their life.

Multi- dimensionally viewing the illness, experience, belief, values and expectation of cancer survivors, brought to light their life and also promote psychological support towards their struggled life.

NURSING RECOMMENDATION

Administrator in nursing are challenged to undertake the health needs of the most vulnerable population by effective organization and management.

Nursing administrator should plan the discussion section weekly for the nurses to organize and discuss the non communicable disease condition which is leading and prone to get the higher incidence and also encourage to do paper presentation regarding treatment regimens, care and support.

Research is the process of finding the new things. In qualitative study understand the feelings and worries of the subject, living experiences after disclosure and also their illness level and their expectations in life could be identified.

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