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Lived Experience of Cancer Patients and Their Family Members in a View to Developing A Nursing Care Guideline for the Nursing Personnel at Selected Cancer Institute, Puducherry



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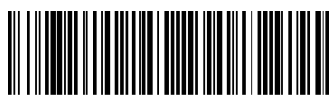
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ABSTRACT

Everyone's life is changed by the diagnosis of cancer. It significantly weighs down humanity. This study sought to understand the lived experiences of cancer patients and their loved ones. A semi-structured interview schedule was used to extract participant experiences relating to their physiological, psychological, socioeconomic, spiritual, and cultural dimensions. A qualitative methodology based on a phenomenological framework was used. Sixteen cancer patients and their family members were selected by purposive sampling technique. The phenomenological methodology of Colaizzi was used to analyze the data. The following seven themes emerged for cancer patients: everything in life has changed; acceptance of the illness; desire to be with loved ones; desire to fulfill their roles; feeling of powerlessness and hopelessness; stress; and having confidence in god. The five themes that arose for their family members were: having trouble sleeping; feeling like they have more obligations; having worries and anxieties; being unhappy; and having faith in god. These findings also highlight crucial areas that call for immediate, intensive action to improve care for cancer patients and their families and thus, their quality of life.



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INTRODUCTION:

“Cancer is going to be a chapter in your life, not the whole story.” Joe wasser

Cancer is a major health problem in India and the world. It is undoubtedly a serious and potentially life-threatening illness. Cancer is a group of diseases characterized by abnormal proliferation, and uncontrolled and unregulated growth of cells. Cancer is a leading cause of death worldwide (WHO, 2015).

Cancer is a life-changing event for everyone's life. It is a major burden on humanity. The cancer experiences challenges not only the individual person but their entire network of affiliation, relationship and support. Individuals with cancer have a higher level of experience that is especially associated with cancer such as cancer diagnosis and treatment implemented to treat cancer. On receiving their cancer diagnosis, the participants perceived that their lives were being threatened and feared deterioration and disease occurrence. In considering their health and willingness to continue living, most of the participants attempted to adopt a healthy lifestyle.

Alleviating the problems faced by patients in the different stages of cancer and their families has drawn substantial public attention, but little is known about the experience of these people.

STATEMENT OF PROBLEM

Lived experience of cancer patients and their family members in a view to developing a nursing care guideline for the nursing personnel at the selected cancer institute, Puducherry.

OBJECTIVES

- To elicit the lived experience of cancer patients.
- To describe the lived experience of their family members.
- To develop nursing care guidelines for nursing personnel.

RESEARCH METHODOLOGY

RESEARCH DESIGN:

A phenomenological approach was employed for this study.

SETTING OF THE STUDY:

The study was conducted in Puducherry cancer trust hospital and Research Centre in Thavalakuppam, Puducherry.

POPULATION

All adults diagnosed with cancer of any body part and those who fulfill the inclusion criteria.

SAMPLE:

Patients receiving cancer treatment in Puducherry cancer trust hospital and research center in Thavalakuppam, Puducherry.

SAMPLE SIZE:

The sample size of this study was 16 cancer patients and their family members visiting OPD and those who fulfilled the inclusion criteria.

SAMPLING TECHNIQUE:

Non probability purposive sampling technique was adopted to select the sample.

TOOLS AND INSTRUMENTS:

PART-I: IDENTIFICATION DATA WITH TWO SECTIONS

SECTION A- Demographic variables of cancer patients and family members such as Sex, Age, Religion, Marital status, Education, Occupation, Socioeconomic status, Cancer type, Treatment type, etc.

PART-II: LIVED EXPERIENCE OF CANCER PATIENTS AND FAMILY MEMBERS

SECTION A- An open-ended semi-structured interview schedule was used to identify the lived experience of patients with cancer.

SECTION B- An open-ended semi-structured interview schedule for their family members to collect their experience.

DATA COLLECTION PROCEDURE:

The data was collected over a period of 4 weeks at Puducherry Cancer Trust Hospital and Research Centre, Puducherry. Formal written permission was obtained and Confidentiality was assured to all the subjects to get their co-operation throughout the process of data collection. Each person was explained about the purpose of the study and written consent was obtained. Sixteen cancer patients and their family members with the experience of cancer were selected by using a purposive sampling technique. One sample was recruited per day. Data was collected by using semi- structured interview schedule and the duration was about 30- 45 mins for each sample.

INTERVIEW PROCESS:

Informed consent was obtained from all participants and individuals were assured of confidentiality. In total, the researcher Conducted 32 patients who qualified to participate in this study. According to their convenience appointments were taken from the patient and their family member. The interviews were conducted in a quiet room by using a semi-structured interview schedule. The voice recorder was used to record the data. The participants were interviewed using a face-to-face method based on the interview schedule. The interview began with an open-ended question with few probing questions to explore in depth of their experiences. The average time was 30-45 minutes to complete the session of the interview schedule.

DATA ANALYSIS:

In this research, the analysis of interview transcriptions was based on Colaizzi's phenomenological methodology. In Colaizzi's approach, the seven procedural steps of analysis were follows.

ETHICAL CONSIDERATIONS:

Prior to the data collection written permission was obtained from the Institution Research Committee. The study was conducted in Puducherry Cancer Trust Hospital, Puducherry. After getting permission obtained from the concerned authority. The selection of the sample was based on inclusion criteria. Each individual subject was informed about the purpose of the study. Informed consent was obtained from the subjects both orally and in written form. The subject

had the freedom to withdraw from the study at any time. No physical or psychological harm was caused. The subjects were assured about the confidentiality of the study.

DATA ANALYSIS AND INTERPRETATION

The data collected from this study were analyzed according to Colaizzi's phenomenological data analysis method and the collected data was organized, tabulated and analyzed by using Colaizzi's phenomenological approach as follows.

ORGANIZATION OF DATA

Section A: Baseline information of the participants

BASELINE INFORMATION OF THE PARTICIPANTS

TABLE 1: Frequency and percentage distribution of demographic variable (n=16)

Characteristics	Category	Patient (n=16)		Family members (n=16)	
		N	%	N	%
Age in years	a) 20-30yrs	-	-	6	37.5
	b) 31-40 yrs	3	18.75	3	18.75
	c) 41-50yrs	6	37.5	3	18.75
	d) ≥50 yrs	7	43.75	4	25
Gender	a) Male	3	18.75	4	25
	b) Female	13	81.25	12	75
Religion	a) Hindu	12	75	12	75
	b) Muslim	2	12.5	2	12.5
	c) Christian	2	12.5	2	12.5
	d) Others	-	-	-	-
Educational status	a) Up to high school	3	18.75	2	12.5
	b) Higher Secondary	12	75	9	56.25
	c) Under- graduation	-	-	4	25
	d) Post-graduation	1	6.25	1	6.25
Occupation	a) Unemployed	8	50	8	50
	b) Employed	6	37.5	6	37.5
	c) Retired	-	-	1	6.25
	d) Business	2	12.5	1	6.25
Type of family	a) Nuclear	11	68.75	11	68.75
	b) Joint	5	31.25	5	31.25
	a) Married	13	81.25	13	81.25

Marital status	b) Single	-	-	3	18.75
	c) Widow	3	18.75	-	-
	d) Divorced	-	-	-	-
Family history of cancer	a) Yes	2	12.5	2	12.5
	b) No	14	87.5	14	87.5
Duration of illness	a) Less than 6 months	7	43.75	7	43.75
	b) 7months -1 year	3	18.75	3	18.75
	c) 1-2 yrs	5	31.25	5	31.25
	d) ≥ 2 yrs	1	6.25	1	6.25
Previous treatment	a) Surgery	7	43.75	7	43.75
	b) Chemotherapy	2	12.5	2	12.5
	c) Radiation	6	37.5	6	37.5
	d) Others	1	6.25	1	6.25
Ongoing treatment	a) chemotherapy	11	68.75	-	-
	b) Surgery	-	-	-	-
	c) Radiation	4	25	-	-
	d) Others	1	6.25	-	-
Other significant data	a) Yes	10	62.5	9	56.25
	b) No	6	37.5	7	43.75

The above table shows the frequency and percentage distribution of demographic variables. The findings were that 7(43.75%) were in the age group of > 50 years. most of them 13(81.25%) were females and 12(75%) were Hindus. About 11(68.75%) were living in nuclear family. In respect to educational status, 12(33.3%) completed their high school education and 8(50%) were unemployed. With regards to illness 7(43.75%) were in the duration of 7 months-1year. About 2(12.5%) of the patients had a family history of cancer, 13(81.25%) were married. As far as previous surgery treatments of cancer 7(43.75%) and 2(12.5%) patients undergoing chemotherapy and 6(37.5%) were radiation therapy, other significant of data 10(62.5%) were suffering from any other co-morbidity.

In socio demographic analysis of family members reveals that 6(37.5%) were aged between 20-30 yrs, 12(75%) were females and 12(75%) were Hindus. In respect to educational status 9(56.25%) had high school education. About 2(12.5%) had family history of cancer. As far as occupation is concerned, 8(50%) were unemployed and 13(81.25%) were married. With regards to other significant of data 9(56.25%) were co-morbidities like diabetes or hypertension and other significant illness.

This chapter also contains a description of the social demographic data of the patients aimed at providing a background to the results presented. The baseline information of the patients was tabulated in the table. The codes used for naming the patients is Alphabets 'A' to maintain the confidentiality to the data. In the present study 16 participants participated. They were coded as 1A, 2A, 3A, 3A up to 16A and their baseline information is also elicited in the subsequent columns.

SECTION B

Table 3. THEMES FOR PATIENT

THEMES	SUBTHEMES
1. PHYSIOLOGICAL EXPERIENCE OF PATIENT	<ul style="list-style-type: none"> ➤ Everything has changed in life ➤ Acceptance to the illness
2. PSYCHOLOGICAL EXPERIENCE OF PATIENT	<ul style="list-style-type: none"> ➤ Wishing to be with their dear ones ➤ Wishing to fulfill their role ➤ Feeling of helplessness and hopelessness
3. SPIRITUAL EXPERIENCE OF PATIENT	<ul style="list-style-type: none"> ➤ Having faith in god

Theme 1: PHYSIOLOGICAL EXPERIENCE OF PATIENT

1.1 Everything has changed in life:

A major concept arose from the participants' sense that they felt different after their diagnosis and treatment.

5A said, "It's terrific all my hair fell down everything changed.

1.2 Acceptance to the illness:

The theme of accepting a certain amount of dependency with grace and dignity across texts.

7A expressed that “I was lack of doing my work, Once upon a time I was strong man never afraid about anything but now I am telling it my family after my death no one should cry for me, that's it.”

Theme 2. PSYCHOLOGICAL EXPERIENCE OF THE PATIENT

2.1 Wishing to be with their dear ones

Almost all of the participants expressed their wish to be with dear ones. 6A expressed that, “I need to see my children's marriage. I can't leave my home alone.”

2.2 Wishing to fulfill their role

Participants were trying to fulfill their personal role, as they felt that they were responsible for it and explained that they were satisfied while doing so.

1A said, “Sometimes I feel still I need to live few more years for my children's marriage.”

2.3 Feeling of helplessness and hopelessness

Patients with cancer felt helpless because of their physical limitations, as they were unable to do their activities, and were dependent on others.

12A stated that as, "Having two kids and having no one to support me and to bring back my kids from school everything has changed since then” and 9A stated that, “lost my hope and peace.”

Theme 3. SPIRITUAL EXPERIENCE OF THE PATIENT

3.1 Having faith in God

In the spiritual context, almost all participants had faith belief, anger and acceptance towards spiritual concern.

12A, 1A, 6A were stated as "God has the power to heal my illness",

SECTION C

THEMES FOR PATIENTS FAMILY MEMBERS

THEMES	SUBTHEMES
1. PHYSIOLOGICAL EXPERIENCE OF FAMILY MEMBERS	Feeling Sleeplessness
2. SOCIOECONOMICAL EXPERIENCE OF FAMILY MEMBERS	The feeling of added responsibility
3. PSYCHOLOGICAL EXPERIENCE OF FAMILY MEMBERS	Living with fears and uncertainty Feeling Depressed
4. SPIRITUAL EXPERIENCE OF FAMILY MEMBERS	Believing God

THEME 1. PHYSIOLOGICAL EXPERIENCE OF FAMILY MEMBERS:

1.1 Feeling Sleeplessness:

While taking care of their dear ones, caregivers might feel common symptoms such as tired, sleeplessness and giddiness. Following are the statements of family members on this aspect.

Few participants stated that “I lost my sleepiness and felt very tired” and “I can't sleep”.16B, 12B, 5B and 7B.

THEME 2. SOCIO ECONOMICAL EXPERIENCE OF FAMILY MEMBERS:

2.1 Feeling of added responsibility:

Disturbing the family balance, due to the disease process was also expressed by the family members as verbalized verbatim stated below:

12B respondent that “I can't do everything ...it is breaking me down” and “Now seeing my mother recover I feel confident now, so I'm taking care.

THEME 3. PSYCHOLOGICAL EXPERIENCE OF FAMILY MEMBERS:

3.1 Living with fears and uncertainty:

The majority of family members were struggling with fear of prognosis the cancer. They fear about the pain episodes and the sufferings of the patients. They even fear about future occurrence of cancer among other family members.

Most of the participants were living with fear and uncertainty about their family member's illness. 6B said that *"I'm feeling more stressed"*.

3.2 Feeling Depressed:

All the participants expressed loss of happiness in the family. Due to their illness patient's family members were emotionally feeling depressed about their loved ones they expressed that 9B stated that *"Lots of worries."*

THEME 4. SPIRITUAL EXPERIENCE OF FAMILY MEMBERS:

4.1 Believing God:

Questioning God and seeking answers from God seemed to be a primary strategy to with the illness. It was hard to find the line between asking questions and questioning God among the family members.

Eight participants stated that, *"Believe in god nothing goes wrong"* and *"I believe in God"*.

DISCUSSION

The study was conducted to elicit the lived experience of cancer patients and their family members in a view to develop a nursing care guideline for nursing personnel at Puducherry Cancer Trust Hospital and research center, Puducherry. This chapter presents the main findings and its discussion.

SECTION B - 1. LIVED EXPERIENCE OF CANCER PATIENTS

The first objective of the study is to elicit the lived experience of cancer patients

THEME 1. PHYSIOLOGICAL EXPERIENCE OF PATIENT:

1.1 Everything changed in life:

In this study researcher identified that the patients experienced a change in almost all spheres of life. They described changes in their body change, body functions, routines and family roles. A similar study conducted by **FaridehYaghmaie (2018)** a qualitative study to assess the physiological needs of cancer patients. The results showed that the pain and loss of appetite were lowest and quality of life was highest among cancer patients.

1.2 Acceptance to the illness:

In this study it was noticeable that In spite of strong self-concepts, the participants consistently admit to an ever increasing need to rely on others for a variety of things they formerly handled themselves. A similar study was conducted by **Anusavio et al., (2014)** to explore the lived experience of cancer patients and their family members in a view to develop a palliative care guideline for the nursing personnel.

THEME 2. PSYCHOLOGICAL EXPERIENCE OF THE PATIENT:

2.1 Wishing to be with their dear ones:

In this study almost all of the participants expressed their wish to be with dear ones. They shared that they would be happier if they could have with their family.

2.2 Wishing to fulfill their role:

In this study the Participants were trying to fulfill their personal role, as they felt that they were responsible for it and explained that they were satisfied while doing so. A similar study was conducted by **CM Carolan (2016)** to explore the lived experience of psychological distress in cancer patients and revealed four themes: being stressed, being isolated, wishing to fulfill their role and wish to be with their family.

2.3 Feeling of helplessness and hopelessness:

In this study the Patients with cancer felt helplessness because of their physical imitation, as they were unable to do their activities, and were dependent on others. This theme has 3 sub-themes. They are physical, emotional and financial.

A similar study was conducted by **Elisabeth coyne (2016)** to explore the breast cancer experiences from the perspective of young people. The findings revealed that the women consider they are too young to assume 'the sick role' and are not prepared for its sudden onset, and neither are their support networks.

2.4 Being stressed:

In this study most of the participants were feeling stress due to their health condition and their family burden due to this illness. A similar study was conducted by **Lovely Antony, et al., (2018)** to assess Stress, Coping, and Lived Experiences among Caregivers of Cancer Patients. The conclusion was drawn that Caregiving is stressful; and challenging and can impact the caregiver's physical, emotional, psychological, and social well-being.

THEME 3. SPIRITUAL EXPERIENCE OF PATIENT:

3.1 Having faith in god:

In this study the Patients with cancer felt their lives is uncertain and death can attack them at any time. This made them feel more powerless and helpless. The study findings of **Maryam Rassouli (2015)** conducted a qualitative study on the spiritual needs of cancer patients. The results revealed that having faith in God helps the patients to cope up with the prognosis of cancer to some extent.

SECTION C - LIVED EXPERIENCE OF FAMILY MEMBERS OF PATIENTS WITH CANCER

To describe the lived experience of family members.

THEME 1. PHYSIOLOGICAL EXPERIENCE OF FAMILY MEMBERS:

Feeling Sleeplessness:

In this study it was noticeable that while taking care of their dear ones, care givers might feel common symptoms such as tired, sleepiness and giddiness. A similar study was conducted by **Fronczek AE, (2017)** to explore a phenomenological study to assess the lived experience of family caregivers with head and neck cancers at two hospital systems providing regional cancer care among 9 family caregivers at New York. The results revealed that five major themes emerged; loss of peace, loss of sleep, feeling alone, and being depressed and fear of the future. The conclusion was drawn that family caregivers of patient with head and neck cancer play a fundamental role in the care of patients, including meeting specific physical and psychosocial needs.

THEME 2. SOCIO ECONOMICAL EXPERIENCE OF FAMILY MEMBERS:

2.1 Feeling of added responsibility:

In this study all the family members expressed a feeling of added responsibility related to the ability to perform the roles of the affected person. Family members are struggling to maintain equilibrium in the family.

A similar study was conducted by **Uqur et al (2014)** on responsibilities and difficulties of caregivers of patients in a daily treatment center in a university hospital. The study concluded that the caregivers had added responsibilities towards the cancer patients.

THEME 3. PSYCHOLOGICAL EXPERIENCE OF FAMILY MEMBERS:

3.1 Living with fears and uncertainty:

In this study Family members were struggling with fear of the prognosis the cancer. They fear about the pain episodes and the suffering of the patients. Family members expressed that they are hanging on to hope, drifting among the new events coming to them.

3.2 Feeling Depressed:

Family members expressed their issues related to unhappiness. Emotional responses included anger, weakness, exhaustion, grief, and sadness. A similar study was conducted by **Cossu G, et.al, (2018)** to assess the psychological perception of colorectal cancer (CRC). It was concluded that the decision-making process can finally be influenced by the healthcare background in which the intervention is promoted and screening programs are carried out.

THEME 4. SPIRITUAL EXPERIENCE OF FAMILY MEMBERS:

4.1 Believing God:

In this study majority of family members used idols, and pictures of God, and followed spiritual behaviors such as prayer and forgiveness as coping mechanisms. A similar study was conducted by Kazem Zendedel (2015) a Qualitative Study to assess the Spiritual Needs of Cancer Patients among 18 cancer patients, referred to the Cancer Institute of Imam Khomeini Hospital in Tehran. Results revealed that the Spiritual needs of cancer patients should be recognized, realized, and considered in care of patients by the medical team.

CONCLUSION:

The study was to elicit the lived experience of cancer patients and their family members in a view to developing a nursing care guideline for nursing personnel at Puducherry cancer trust hospital and research center, Puducherry. The results of this study concluded that the lived experience of cancer patients and their family members faces dramatic, extraordinary transformation in their life. The challenge nurses to be more conscious of the nature and difficulties that not only patient, family members too encounter. These findings also indicate the

important aspects which require intense and prompt action to be taken to improve the care of cancer patients and their family members to improve the quality of life.

RECOMMENDATIONS FOR FUTURE STUDY:

- Similar study can be conducted in other parts of the country.
- The same study can be conducted in different settings.
- The study can be replicated with larger samples for better generalization.
- The study can be done as a longitudinal study.
- A mixed research design of qualitative and quantitative methods may be valuable for further studies of cancer patient's experiences.

LIMITATIONS:

- Getting cooperation for recording the data was difficult for a few female patients because they felt shy to explore their experiences.

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