A Qualitative Study To Assess The Lived Experience Of Cancer Patients And Their Family Members In A View To Develop A Palliative Care Guideline For The Nursing Personnel At Selected Hospital, North India

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Abstract:
This paper talks about the the lived experience of cancer patients and their family members in a view to develop a palliative care guideline for the nursing personnel at selected hospital, North India. The objectives for the study was to elicit the lived experience of cancer patients, to elicit the lived experience of family members of cancer patients. To identify the needs of cancer patients and family members for developing a palliative care guideline for the nursing personnel. The study results shows that The patient experienced lack of control during this period which is described as an experience of existential changes. The essence of the phenomenon, experience of living with cancer, was to regain a control over the existential changes i.e. the present situation and one‘s own body. This period was described as an irrevocable time that people had to manage and get through. The essence of the phenomenon emerged from ten descriptive themes. The ten themes emerged from the data of the cancer patients and the 6 themes emerged from the data of their family members were shown to be incorporated within the four existential of the everyday world, lived body, lived relationship, lived time and lived space.

Keywords: Lived experience, Cancer patient, Family members, Palliative care, Nursing Personnel.

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INTRODUCTION :

News about the dangers of infectious diseases like HIV/AIDS and avian influenza capture headlines around the world, but the number one cause of human deaths worldwide is a non-communicable, non-infectious disease known as Cancer.

Of the 10 million new cancer cases seen each year worldwide, 4.7 million are in developed countries and nearly 5.5 million are in developing countries. Although the disease has often been regarded principally as a problem of the developed world, more than half of all cancers occur in developing countries. On the growing burden of cancer in the world, European Society of Medical Oncology declared that: "Cancer will replace cardiovascular diseases as the number one killer in the world this year. According to International Agency for Research on Cancer (I.A.R.C.), the global burden of cancer doubled during the last 30 years. In 2008, it is estimated that there were 12.7 million new cases of cancer diagnosed worldwide, 7.6 million deaths from cancer and 25 million people are still alive five years after diagnosis. [1]

Cancer is currently the cause of 12% of all deaths worldwide. In approximately 20 years time, the number of cancer deaths annually will increase from about 6 million to 10 million. Yet cancer is, and has been relatively neglected in developing countries. Cancer will become an increasingly important cause of premature mortality in the developing countries as their population expands, tobacco consumption increases, diets are westernized and new life styles are adopted. [2]

Cancer prevalence in India is estimated to be around 2.5 million, with over 800,000 new cases and 550,000 deaths occurring each year due to this disease in our country. The common sites for cancer in India are oral cavity, lungs, esophagus and stomach in males and cervix, breast and oral cavity among females. More than 70% of the cases reported for diagnosis and treatment services are in the advanced stages. This has led to a poor survival and high mortality rate. [2]

According to Continuum Cancer Centres of New York, anorexia is present in 15 to 25 percent of all cancer patients, and it is almost universal in patients with advanced disease. It is the most common cause of decreased nutrient intake which triggers malnutrition and progressive exhaustion from hunger. Cachexia is a clinical wasting syndrome marked by weakness, progressive loss of body weight, fat, and muscle. It has been estimated that one half of all people with cancer experience cachexia. And in two thirds of all patients with progressive cancer, anorexia and cachexia frequently occur together. [5]

There are four standard methods of treatment for cancer: surgery, chemotherapy, radiation therapy, immunotherapy and biologic therapy. Chemotherapy and radiation therapy and sometimes even biologic therapy to cancer can damage the salivary glands, which may cause dry mouth, mouth sores, tender gums, which leads to dental problems or mouth infections, such as thrush. Nausea can be a side effect of cancer treatments like surgery or chemotherapy . It can also be caused by certain types of cancer or other illnesses. Vomiting may followed by nausea and may be caused by cancer treatment, food odours, an upset stomach, or bowel gas. Some people even vomit when they are in places (such as hospitals) that remind them of cancer. Patients may also have dry heaves, which occur when body tries to vomit even though, stomach is empty. Diarrhoea also can be caused by cancer treatments. These treatments cause diarrhoea because they can harm healthy cells, in the lining of large and small bowel. [6]

Regardless of the prognosis, the initial diagnosis of cancer is still perceived by many patients as a life-threatening event, with over one-third of patients experiencing anxiety and depression. This year's theme of the mental health day is "Mental Health and Chronic Physical Illness- Need for Continued and Integrated Care." Physical and mental health problems go hand in hand. Persons with physical illnesses like heart diseases, diabetes, cancer and chronic respiratory illness suffer more from depression and anxiety disorders than healthy persons. A person who suffers from this type of physical illness has increased risk of developing mental disorders like depression and anxiety. The prevalence of depression among diabetic and heart patients is 20%, and 25-39% in cancerpatients. [7]

Therefore the researcher felt the need to explore the lived in experience of not only cancer patients but also care givers. As the experience of the patient is unique in itself, and cannot be reduced merely to a scientific account of disease or to a personal treatment, it rather needs to be considered with context of lives. To gain better understanding on the experience of patients with advanced stage of cancer, qualitative approach is the best way.

The formation of new guidelines on the therapeutic, psychosocial and legal needs of cancer care is essential to safeguard the interests of oncology nurses. This will enable the nurses to understand patient‘s needs and problems and render appropriate and comprehensive care. This in turn will give hope and help to achieve good quality of care. The emphasis will be to look at the provision of safe, effective, and compassionate care, to support in a holistic way and to educate our patients, families, staff, colleagues, and community fulfilling the individualized needs of cancer patients and their family members. Therefore, the researcher was interested in exploring the lived experience of patients and their family members.

STATEMENT OF THE PROBLEM

A Qualitative Study To Assess The Lived Experience Of Cancer Patients And Their Family Members In A View To Develop A Palliative Care Guideline For The Nursing Personnel At Selected Hospital, North India

OBJECTIVES OF THE STUDY

1. To elicit the lived experience of cancer patients
2. To elicit the lived experience of family members of cancer patients.
3. To identify the needs of cancer patients and family members for developing a palliative care guideline for the nursing personnel.

ASSUMPTIONS

- The essential truth about reality can be identified by eliciting the lived experience of patients and their family members.
- The perception of phenomena varies with each individual

METHODOLOGY

RESEARCH DESIGN

A phenomenological approach using descriptive analysis was utilized to explore the human experience of the phenomena under scrutiny.

SETTING

The setting of the study was a selected 300-bedded Hospital of Madhya Pradesh , dedicated exclusively for palliative care for patients with terminally ill cancer or advanced cancer. Permission was obtained from hospital authorities prior to the study.

SELECTION OF PARTICIPANTS

Population consists of patients with advanced stages of cancer admitted for palliative care, during the study period of 6 weeks and their family members staying and caring for him/her. Participants were recruited through convenient sampling.

INCLUSION CRITERIA

- Patients who had at least a family member caring for them since the diagnosis of cancer.
- Potential participants, both males and females were adults, 20 years of age or over and were able to give informed consent.
- Patients who were conscious and oriented.
- Participants were selected regardless of whether or not they chose to continue withtreatment or refused further treatment.
- Patients and family members who were willing to participate

- Patients and family members who could understand Hindi and English were selected for the study.

EXCLUSION CRITERIA

- Patients who were critically ill
- Participants who couldn‘t speak or who had hearing problem.

TECHNIQUE OF DATA COLLECTION

Baseline information, including age, gender, education, diagnosis, length of disease, stage of disease, occupation, medications prescribed, economic status, and relationship with the family member was obtained through a simple questionnaire that was completed before the audiotaped portion of the interview.

An in-depth interview process was utilized using predetermined questions, which kept the interviewee focused yet still allowed clarification of feelings and probing of issues raised. Interviews were recorded and verbatim were transcribed, and they were then subsequently printed for further manual analysis. The Colaizzi methodological approach was chosen to investigate the phenomena of interest in this phenomenological qualitative research study, because it identifies the phenomenon as it is experienced.

VALIDATION OF THE TOOL

Seventeen persons validated the Tool used for this study: a doctorate in psychiatric nursing, one psychiatrist, two consultants in pain and palliative medicine, one oncologist, six professors in nursing, two palliative social worker, and four associate professors in nursing. Suggestions were incorporated and tool was modified.

TOOLS

Two tools were prepared. Each had two sections:

Tool -1 Identification data with two sections again.

- **Section A:** It consisted of structured items designated to collect the background information of patients related to age, education, employment status, marital status, monthly income of the family, actual medical diagnosis, stages of cancer and present medications they were on.
- **Section B**: Details of immediate family member‘s such as age, gender, relation, education and occupation.

Tool 2:-Lived experience of patients and their family members.

This tool consists of two sections as follows**:**

- **Sections A:** An open-ended semi structured interview schedule was used to identify the lived experience of patients with cancer. This tool consisted of one main leading question as ―Describe your experience with your illness.‖ The other five questions regarding other aspects like physical, psychological, spiritual, financial and social along with their prompters were used only as guide questions, to probe the patient to get detailed information. The probe questions were developed after interviewing 2-3 patients and the formation of the questions were like ―Could you please share your problems that you are facing due to this disease‖, ―How did this illness affect your life?
- **Section B**: An open-ended semi structured interview schedule for their immediate family members, to collect their experience. The family members of the patients were asked similar open-ended questions to explore the experience in caring of the patient with advanced cancer, such as ―How did you feel while you are caring for him/her? How did his/her illness affect your life.

PLAN FOR DATA ANALYSIS

Phenomenology, to recapitulate, is the philosophical method in which one articulates the lived experience of being present in the world. Various methods are used in phenomenological data analysis. The most commonly used methods for phenomeno logical data analysis are Voethan Kaam, Giorgi and Colaizzi‘s methods. [8] In this research, analysis of interview transcriptions was based on Colaizzi‘s phenomenological methodology.

RESULTS :

SECTION A. BASELINE INFORMATION OF THE PARTICIPANTS

Table-1: Frequency and percentage distribution of sample characteristics :

Characteristics	**Category**	**Patient (n=12)**		**Family members (n=12)**	
		N	**%**	**N**	**%**
Gender	Male	2	16.67	4	33.33
	Female	10	83.33	8	66.67
Age in years	20-30yrs	4	33.33	8	25
	31-40yrs	3	25	2	16.67
	41-50yrs	1	8.33	2	16.67
	>50yrs	4	33.33	5	41.66
Type of family	Nuclear	9	75	9	75
	Joint	3	25	3	25
Education	Up to high school	2	16.67	6	50
	Pre degree	1	8.33	1	8.33
	Degree	5	41.67	3	25
	Post-graduation and Above	4	33.33	2	16.67
Occupation	Un employed	4	33.3	6	50
	Employed	6	50	3	25
	Retired	2	16.67	0	0
	Business	0	0	3	25
Duration of illness	Less than 6 months	2	16.67	2	16.67
	7months -1 year	6	50	6	50
	1-2 year	3	25	3	25
	> 2 years	1	8.33	1	8.33
Family history of cancer	Yes	0	0	0	0
	No	12	100	12	100
Area of living	Rural	5	41.67	7	41.67
	Urban	7	58.33	5	58.33
Previous treatment	Surgery	9	75	-	-
	Chemotherapy	12	100	-	-
	Radiation	7	58.33	-	-
	Others like blood Transfusion	5	41.67	-	-
Family history of cancer	Yes	0	0	0	0
	No	12	100	12	100
Area of living	Rural	5	41.67	7	41.67
	Urban	7	58.33	5	58.33
Previous treatment	Surgery	9	75	-	-
	Chemotherapy	12	100	-	-
	Radiation	7	58.33	-	-
	Others like blood Transfusion	5	41.67	-	-
Marital status	Married	8	66.67	9	75
	Single	2	16.67	1	8.33
	Widow	1	8.33	1	8.33
	Divorced	1	8.33	1	8.33
Ongoing treatment Other co morbidity	Palliative chemotherapy	1	8.33	-	-
	Symptomatic treatment	12	100	-	-
	Specific treatment	7	58.33	-	-
	Yes	4	33.33	4	33.33
	No	8	66.67	8	66.67

Table 1: In this section the baseline data obtained is analyzed. The frequency and percentage distribution of socio demographic variables of patients revealed that 33.3% were in the age group of > 50yrs and another 33.33% 41-50yrs, 13.3% in 20-30 years age group and 25% were in the age group of 31-40yrs. Majority of the patients were females (83.33%) and about 75% were living in nuclear family. About 33.3% had post-graduation level of education and 41.67% of them had degree. Majority (50 %) were employed and 33.33% were unemployed. Majority (58.33%) were residing in rural areas. Most of the patients (50%) had illness duration of 7 months-1 year and 25% had illness duration between 1-2 years. None of the patients had a family history of cancer. Majority (66.67%) were married. All (100%) had a history of chemotherapy and 75% had surgeries like, PEG tube insertion, colostomy, and tumor excision surgery. All (100%) of patients are getting symptomatic treatment and 58.33% is getting specific treatment like antibiotics and seizure prophylaxis. Majority (66.67%) were free from any other co morbidity.

In socio demographic analysis of caregivers reveals that majority (41.66%) were in the age group of >50yrs and comparing the gender it is noted that majority (66.67%) were females. Majority About 50% had high school level of education and 33.33% had post- graduation level. None (0%) had family history of cancer. Majority (50%) were unemployed and majority (75%) were married. About 33.33% had co morbidities like diabetes or hypertension.

SECTION B: LIVED EXPERIENCE OF THE CANCER PATIENTS ESSENCE OF THE PHENOMENON

The patient experienced lack of control during this period which is described as an experience of existential changes. The essence of the phenomenon, experience of living with cancer, was to regain a control over the existential changes i.e. the present situation and one‘s own body. This period was described as an irrevocable time that people had to manage and get through. The essence of the phenomenon emerged from ten descriptive themes.

SECTION C: LIVED EXPERIENCE OF FAMILY MEMBERS OF PATIENTS WITH CANCER ESSENCE OF THE PHENOMENA

The lived experience was described in its entirety which reflects the challenges that the family members of the patients faced in living with a condition that is not recognized or widely discussed. These six themes gave a structure presenting the essence: balancing a changed life situation in fear and uncertainty.

The ten themes emerged from the data of the cancer patients and the 6 themes emerged from the data of their family members were shown to be incorporated within the four existentials of the everyday world, lived body, lived relationship, lived time and lived space (Van Manen 1990).

CONCLUSION

The cancer experience creates many different circumstances. Cancer brings mortality into focus, yet family members in the balanced new world understand that loss is a possibility without being completely overwhelmed by its potential and are able to have hope. The way the family deals with these circumstances determines which –world‖ they are in.[9] This type of work provides a unique perspective of this coevolved journey of cancer with families and their collaborative helpers.

Professional support is an essential element of the illness trajectory. Understanding the lived experience of patients with cancer can help nursing and medical practitioners to provide proficient care that meets the continual needs of their patients. It helps the patient to maximize the benefits of treatment and to live as well as possible with the effects of the disease.

This study can serve as a guiding, preliminary source of information for future studies. Another limitation is the use of families dealing with different forms of cancer, which limits the study‘s ability to explain unique and similar aspects of different types of cancer. However, the major themes emerged from the experience of cancer patients and their family members can give some indications of common difficulties with several forms of cancer. Finally, it should be noted that interviewing procedures are geared toward clients with good verbal abilities, and further research using creative designs may be needed to assess the experiences of family members who are less articulate or open with their feelings.

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