

## **THE EXPERIENCES OF ADVANCED CANCER PATIENTS AND THEIR CAREGIVERS IN A PALLIATIVE CARE UNIT: AN ANTHROPOLOGICAL STUDY**

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Palliative care is a holistic approach that tends to manage the advanced cancer patients. The present study was conducted in a palliative care unit to understand the experiences of advanced cancer patients and their families. A total of 30 advanced cancer patients were repeatedly interviewed using an interview guide. The qualitative data was divided into various themes: uncertainty of life associated with cancer, importance of time, ethical responsibility of a doctor, truth telling to the patient, family collusion and God's role in life and death. Importance of time was found to be the most important concern among the caregivers of the respondents. It was found that in order to deal with the concerns of advanced cancer patients and their families, it is important to create awareness about cancer, educate family members regarding open communication and enable patients to participate in their decision-making process.

**Keywords:** Advanced cancer; Palliative care; Family collusion; Uncertainty of life.

### **Introduction**

Palliative care is the care and management of the patients with active, progressive, far-advanced disease for whom the treatment is limited and the focus of such a care is quality of life. Hospice is a type of care that focusses on the palliation of a terminally ill patient's symptoms. These symptoms can be physical, emotional, spiritual or social in nature. Hospice is an important part of palliative care. Hospice care focusses on bringing comfort, self-respect, and tranquility to the dying patients.

### **Research Methodology**

With a view to anthropologically understand the experiences of advanced cancer patients and their families, a study was conducted in the palliative care unit of PGIMER, Chandigarh (India). This unit was started in February 2000 by Indian Red Cross Society, Chandigarh in collaboration with PGIMER, Chandigarh to provide continuity of care to the patients whose active treatment is not possible. A total of 30 patients (16 females and 14 males) and their family members were observed and interviewed repeatedly using an interview guide during their visit to the palliative care unit.

For the present study, the ethical clearance was obtained from Panjab University Institutional Ethics Committee. The written informed consent was also obtained from the respondents or atleast one of their caregivers after explaining the research

objectives clearly. While interviewing, it was made sure that the respondents do not get disturbed or emotional distressed. To make this sure, the formal interview were not taken rather the researcher accompanied the cancer patient and their family members during the treatment. During this time period, informal interviews were conducted and observations were made.

### **Results**

The mean age of all respondents in the present study was 46.88 (45.88 for males and 47.84 for females). The differences between the mean ages of males and females were non-significant. The ages of the respondents ranged between 22 to 78 years. Only 33.3 per cent of the advanced cancer patients were aware about their diagnosis while 66.7 per cent were unaware. Only 13.3 per cent of these advanced cancer patients were aware of their cancer prognosis while other were completely unaware.

The qualitative data was analysed thematically and the following three major themes emerged: first encounter with family of an advanced cancer patient, communication and collusion and concerns at end-of-life.

#### **First Encounter with Family of an Advanced Cancer Patient**

On the very first day of my visit to the palliative care unit, one of the doctors introduced me to a middle aged man whose mother was critically ill and admitted in the emergency. With no clear idea of how to start data collection, I chose to observe the conversation between doctor and the patient's son. Excerpts of the conversation are given below:

Caregiver: *How much time is left?*

Doctor: *All is in His hands, pray to God, let His invitation come.*

The caregiver asked the doctor about the time left with the patient. The doctor mentioned that life is in hands of God and he as a doctor can't tell exactly about the time left with the patient. From the careful analysis of similar conversation, it was observed that death is the persistent specter for people who have cancer, and for their families. The cancer patients and their families face time disruption and its appropriation in various ways. In the immediate term, cancer disrupts time and life, awareness of time increases, time is verbalised and reflected. The caregivers of the respondents express their concern about time in the form of following questions such as "*how much time does he/she have? is this the time to tell the near and dear ones about the disease and its stage so that they could come and meet the patient or the patient could be taken to them? is this the right time to take all the pending decisions for the patient?*"

From the careful analysis of similar conversations, it was found that in a palliative care setting, the references to the God and God's will are very common.

The caregivers are told to have faith in God as death and life are believed to be in Almighty's hands.

### **Communication and Collusion**

Open communication in cancer care has gained increasing importance in recent years but there is significant variability in the sharing of prognostic information (Innes and Payne, 2009). In clinical settings in India, there is a common practice of non-disclosure of prognosis and detailed disease-related information to the patient. This is commonly referred to as collusion. Collusion refers to a secret agreement made between clinicians and family members to hide the diagnosis of a serious or life-threatening illness from the patient (Low *et al.*, 2009). In health care, it implies any information (about the diagnosis, prognosis and medical details about the person who is ill) being withheld or not shared among individuals involved (Chaturvedi *et al.*, 2009). It stems from the fear of negative psychological impact of such revelation (Lee and Wu, 2002). The reasons for collusion include the belief that cancer is caused due to *karma* and *kismet*, and that cancer is incurable and contagious; and the stigma associated with cancer. Due to this collusion, it was observed that patients ask a number of questions to their doctors which include: *what is the disease am I suffering from? What is the stage of disease? How much has the disease spread? Are there chances of cure or survival? What will be future course of disease? What are the chances of the recurrence of disease and what are its symptoms?*.

In such a situation, it becomes important to take the doctor's perspective. A doctor dealing with advanced cancer patients argued, "*I only respond to their questions*". The doctor highlighted that conversation about the prognosis is not initiated by the doctor but by the caregivers or the patients. On asking what if a patient asks about prognosis, the doctor replied, "*I only answer the questions asked by the patient, if patient asks directly then I am bound to tell little bit of it*". Another doctor from the palliative care unit added, "*We do not ask the patient ourselves whether they want to know about the disease from which they are suffering. We only respond, if the patient asks*".

The doctors, on the one hand, feels that it is their ethical responsibility to tell truth to the patient about the stage of the disease but on the other hand, family wants to hide the prognosis from the patient. In such situations, doctors try to talk to the family and often counsel them to tell the patient about their condition so that they could take their own decisions in time. The concealment of cancer prognosis from the patients is in contrast to the informed consent, self-determination and autonomy, which are guiding principles of biomedical ethics. These principles does not hold true for the present study in which protection of the patient from hopelessness and fear of death, tranquility, family and relationships assume greater importance in face of death. Similar arguments have also been made by Fox (1991), Gordon and Paci (1997), Bosk (1999) and Kleinman (1999).

### Concerns at End-of-life

The three types of concerns were found among cancer patients at end-of-life: financial concerns, health of family members and marriage of family members.

The most important concern of advanced cancer patients was the financial difficulties that their families face due to cancer. A male advanced cancer patient told that his wife left her job to take care of him and they are financially supported by his parents who get a monthly pension. Worried about the expenses of his medication and repeated hospitalisations, he narrated, “*costly treatment of the disease has ruined us*”. Another respondent who was diagnosed in an early stage decided to stop his treatment due to financial difficulties. He later reported in palliative care unit with an advanced disease. Such cases were common in the palliative care unit where the financial difficulties led to delay in treatment.

The concerns such as health and marriage of family members were due to belief that cancer is contagious and the stigma associated with cancer. The belief that cancer is contagious creates a fear within the family in relation to health of other family members. A male respondent (husband of a cancer patient who died of advanced cancer of cervix) told that his wife was diagnosed with advanced cancer when she was pregnant. She was advised to undergo abortion but she did not take into consideration the advice given by doctor. After her pre-mature delivery in seventh month, her treatment was started at PGIMER, Chandigarh but it was already too late. She died three months after her delivery. After her death, her husband was worried about the health of child. He asked a variety of questions about the survival of his child such as: *Will the child be able to survive? Will he also suffer from cancer? At what age the physical examination of the child is required to rule out the possibility of cancer?* These questions clearly pointed toward risk, uncertainty and fear in the mind of father. To his queries, the doctor responded, “*If there is no problem in growth and development of child, then there is no need to worry and to undergo any tests as of now*”. The doctor also explained that cancer is not contagious and is not passed on from mother to foetus in womb.

There was another case where a woman was diagnosed with cancer during her pregnancy. Her in-laws were against her decision of undergoing abortion and wanted her to give birth to child. So, she continued with the pregnancy and at the time of interview, she was seven months pregnant. She had some idea about her advanced disease as she could feel something spreading inside her body. At this time, her only concern was life of her child. She even requested her doctor for a premature delivery so as to save the life of her child. In these cases, the respondents believed that cancer is contagious and associated ‘risk’ with it. In the first case, the caregiver was worried about the health of the child whose mother died of cancer. In another case, the cancer patient was not worried about herself but her unborn child.

The stigma associated with cancer affects the social interaction of cancer patients and their families outside the family unit. This further affects the marriage

prospects of those related to cancer patients. A couple who was suffering from advanced cancers has an unmarried son and a daughter. They were concerned about the marriage of their children. They shared that their cancer diagnosis is a hindrance in way of marriage of their children as most of the people believe that cancer is contagious and spreads from one person to another, and is an incurable disease. A woman with advanced cancer of cervix shared that a large number of people approaches her for the marriage of her son but they do not turn up after knowing about the diagnosis and prognosis of her disease. They fear that the person who stays with a cancer patient throughout the day have the great chances of developing the disease. From the cases, it is cancer patients face difficulty in finding partners for their children as there are a number of myths associated with cancer such as contagious nature of disease and the associated stigma.

### **Discussion**

From the careful analysis of the experiences of advanced cancer patients in palliative care unit, the themes such as uncertainty of life associated with cancer, importance of time, ethical responsibility of a doctor, truth telling to the patient, family collusion and God's role in life and death emerged. Importance of time was found to be the most important concern among the caregivers of the respondents. The time was verbalised and reflected in the conversations between caregivers and health care providers and the caregivers wished to know about exact time which the respondents are left with. There is a common practice of not telling the patients about the prognosis due to the beliefs and stigma associated with cancer. The three types of concerns were found among cancer patients at end-of-life: financial concerns, health of family members and marriage of family members. The financial difficulties were clearly narrated by the advanced cancer patients and their families. The related concerns such as 'risk', 'uncertainty' and 'fear' regarding the health of their family members also emerged. These concerns stem due to the myths associated with cancer and the wide-spread stigma.

In order to deal with the concerns of advanced cancer patients, it is important to create awareness about cancer, educate family members regarding open communication and enable patients to participate in their decision-making process.

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