



# Immediate Psychological Reaction to the diagnosis of terminal illness – A study on caretakers of persons living with cancer

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## Abstract:

*The status of cancer revealed to the patient and family can result in vast number of intense emotions. When medical personnel reveal the news of possibly fatal disease to a family member it may be most upsetting and traumatic experience in a person's life; especially when the patient is a spouse, child, parent, sibling etc. This paper aims to find from a sample population about their initial reaction to the diagnosis of cancer of their loved one. In some in cases cancer can be fatal and in most cases the treatment is long term. This can have great impact on not only patient but also on their primary caretaker. There is a need to protect caretakers from psychological distress caused by disclosure of diagnosis. A total of 120 caretakers of cancer patients were interviewed to know their first reaction to diagnosis and the medical personnel who revealed the diagnosis. Substantial portion of the respondents said that the diagnosis was revealed by the doctor wherein the possibility of doctor and caretaker engaging in discussion about diagnosis and care could be limited and managing their psychological reaction could be a greater matter of concern. The findings call for need for a good team work between the doctor and trained Medical Social Worker in order to improve the informational and emotional care at the time of revealing the diagnosis.*

*Keywords: cancer, diagnosis, disclosure, medical social worker.*

## **Theoretical Framework:**

When medical personnel reveal the news of illness like cancer the psychological reactions of the individual is significant to understand. Clinical observation of Thanatologist Dr Kubler Ross has shown that patients when revealed of their terminal illness state may undergo five reactions. These reactions are; *shock* seen as the initial reaction immediately after knowing diagnosis; *denial* of reality; *anger* on oneself, God, treating doctor, family

members; *bargaining* where in a good behavior is expressed as an effort to survive; *depression* is the next stage when the individual realizes that nothing much can be done to stay away from the problem. The last stage is *acceptance*. As the time goes on and with continuous support and reassurance individual tends to accept the situation and learn to live with it. This stage theory was originally given for patients suffering from terminal illness and when he/she is nearing one's own death. Later this theory was extended to anyone who faces major loss in life (Holland 2014). However each individual is unique and hence the reactions could also differ from person to person.

All people who are revealed of the terminal illness of their family member may not go through these set of emotions in the same order as explained by Kubler Ross and also their resilience could be much better to these reactions. Reactions of a caretaker can depend on age, gender, culture, availability of resources, the environment in which they live and many other such variables. On the other hand, Kubler Ross has given the framework to identify the reactions to any loss and the effect it has on any person. Hence the reactions mentioned in the theory should be considered to help the caretakers of cancer patients to cope with these emotions in a constructive manner as it gives an understanding to the professional medical Social Worker.

The five reactions examined above – denial, anger, bargaining, depression and acceptance are exhibited by many. Souza Elizabeth (1994) reported that the family members experienced shock and had depressive feelings. In the field of Thanatology, Kastenbaum (1977), Kastenbaum, and Aisenberg,(1972), Ross (1969) have made significant contribution by learning how people psychologically react to the diagnosis of terminal illness. According to them, initially many people attempt to deny the fact or else to deny the meaning of those facts. Denial stems from increased anxiety and prevents the threatening thoughts from flowing in consciousness. Some patients might become extremely angry when they receive a diagnosis of terminal illness, as they become overwhelmed with anxiety. Some engage in bargaining as an effort to survive. Depression is a common response to terminal prognosis and can occur immediately or after some delay. Some do arrive at acceptance of the inevitability of death in a peaceful manner and strive to understand and come terms with the meaning of their own lives.

Dr Kubler Ross originally proposed the reactions as stages, although others who have followed her in the study of death and dying have modified her theory in recognition of the fact that a stage model cannot always account for the transitions that patients under go (Schulz and Aderman,1974). Even Kubler Ross did not argue that all stages must occur in a particular order. She recognized that dying is an extremely complex and personal process, affected by a variety of circumstances too vast to be packaged neatly into a set of stages. Nonetheless, health care professionals sometime expect that patients will follow the pattern as it has been presented in Kubler Ross writings (Silver and Wortman,1980). Waldrop (2007) highlights the intense emotions during end stage of cancer. They observed that caregivers experienced multiple losses during the terminal illness of their loved ones. They have also identified the link between caregiver grief and advanced illness. Physical symptoms of sleep disturbance and physical strain were evident. Changes in the nature of their social relationships were also reported. It is to be

understood that, any reactions to the terminal illness if are experienced by the caretakers for a long period of time should be dealt by professionals. Because, these reactions may have impact both on caretakers psychological conditions and their performance as caretakers. Hence identification of these emotions is very important and cancer care has to give importance to caretakers. These studies are important in assuming the point from where the intervention should begin. Disclosing the diagnosis of terminal illness has to be done in a sensitive manner because it is an important milestone in a physician – caretaker – patient relationship and may facilitate treatment and caring plan in an effective manner. Current paper aims at understanding these issues with the aim to explore the role of medical social worker in Oncology care.

Hence objectives of the paper are,

- To analyze the initial reactions of the caretakers of persons living with cancer
- To know the person who revealed the diagnosis to caretakers and to analyse their role in managing the reactions

### **Materials and methods**

Primary caretakers of newly diagnosed cancer patients were the units of this study and it was carried out in a clinical setting. Altogether 120 units were selected considering the inclusion criteria. This included the caretakers of newly diagnosed cases at the time of data collection. Simple randomization technique was used to select the units. Each one of them was briefed about the objectives of the study and data was collected from those who willingly agreed to participate in the study. As this part of the study was descriptive in nature, data was gathered through face to face interview method. Researcher built a good rapport with the caretakers during data collection which was significant in discussing the very sensitive issues of caretaking and its impact on them. Descriptive statistics are used to present the data.

### **Results**

Demographic characteristics of the respondents showed that majority are females (73%). Mean age was 42 years and 73% were married followed by 18% unmarried. Caretakers relationship with the cancer patient shows that majority 33% were spouses, 18% were parents, 10% siblings 32% were children.

It is important to bear in mind the emotional dynamics of the caretakers soon after revealing the diagnosis. In other words the reactions or responses to the diagnosis can be overwhelming. The immediate reaction of the caretakers of this study were recorded in their own words and categorized in the form of reactions presented in Table No 1.1.

**Table No 1.1: Immediate reactions of the caretakers to the diagnosis**

Reactions	F	Percentage
Denial	40	34%
Shocked	46	38%
Anger	3	2%
Bargained	4	3%
Afraid	27	23%
Total	120	100

Out of total 120 caretakers 38% caretakers were shocked. Another 34% denied the diagnosis as this reaction could be a coping mechanism for caretakers who are unable and unprepared to the reality of terminal illness. Another 22% have expressed being fearful. A small portion of caretakers constituting 3 % bargained to prove that the diagnosis can be wrong and 3% expressed anger. These emotional reactions of caretakers are in line with those described by Kubler Ross (1970). On the other hand the study findings also show that all caretakers of current study did not have similar reactions soon after the diagnosis was revealed to them showing only partial reflection of stage theory of Kubler Ross. Above highlighted are the emotional reactions and these are the combinations of the various emotions that are expressed by the caretakers. For eg, when some caretakers said that they refused to talk about the illness to anyone others said they did not take the patient to the oncologist but physician with the belief that it was not cancer. As the researcher could not enter all the emotions expressed by the caretakers they were grouped in the larger emotional reaction of denial. It has to be noted here that no caretaker has accepted the diagnosis and this shows the need for intervention by a counselor to help them accept the situation and go through the stages.

Details about persons through whom the diagnosis was revealed to caretakers is presented in the Table No. 1.2

**Table No 1.2: Revealing of diagnosis**

Person	Frequency	Percentage
Doctor	78	65%
Other family member	42	35%
Total	120	100

Out of total respondents, 65% reported that, concerned doctors revealed the diagnosis to them and remaining 35% stated that other family members told them the diagnosis of cancer. When doctors reveal the diagnosis the chance

for ventilation of emotions could be very low due to the time and other constraints. It is to be noted here that professional Social Workers have not revealed the diagnosis to any of the caretakers. When caretakers are women, often they feel unable to interact and discuss with doctor about conditions of the patient. In such a situation, other family members get to know the diagnosis and through them the caretakers become aware of patients health conditions. When one family member reveals the news to other family member, handling the situation becomes tougher. Identifying the emotions, answering the queries, providing space for ventilation is very important for caretakers to prepare themselves for this special role. Hence revealing the diagnosis becomes a very important component in oncology care. Counselors/ professional Social Workers may be able to do this task by minimizing the reactions. The findings of the above table presents the need for Medical Social Workers in oncology settings

### **Discussion:**

Individual reacts to the news of terminal illness in various ways. Responses differ depending on many factors – personality, emotional maturity, coping strategies, age and culture (Kang, Miller and Lee, 2006). In the current study caretakers' first reaction to cancer status was in different forms like shock denial, fear, bargaining, anger. Shock is a reaction when an individual receives unexpected news wherein she/he appears stunned and shows no reaction. Denial is an adaptive coping strategy and it can be a gradual coping means to come in terms with the situation. However, long term denial can cause problems like resistance with medical team, disagreement for treatment plan etc. Uncertainty of future, life or death related consequences will result in fear. Seriously ill people and their relatives may show anger or aggression. The reaction of caretakers are similar to the ones described by Ross (1970) as reactions to impending loss – denial, anger, bargaining, depression and acceptance. Kubler Ross stage theory says that an individual tends to experience five reactions denial, anger, bargaining, depression, and then ultimately acceptance. All caretakers of current study did not have same reactions when the diagnosis was revealed to them further posing the questions on whether all proceed through these changes as given in stage theory. Caretakers had various feelings which later the researcher grouped into the categories of denial, shock, anger, bargaining and being afraid. Longitudinal studies are advisable in order to know whether the caretakers of cancer patients proceed through the stages and their ability for resilience for every emotion. Nevertheless, the findings shows that when the diagnosis is revealed to the family member it becomes critical and stressful. Thus professional involvement with caretakers is recommended to assist to handle these emotions. Any of these reactions unaddressed through counselling approach will have adverse effects. These reactions may occur several times during the course of caring and often they provide a defense to help individuals cope during stress.

It is oncologists who often reveal the diagnosis to the caretakers and patients (BramelyL, Matili M 2014). Study results showed that none of the caretakers were assisted by counselors or Medical Social Workers when the diagnosis was revealed to them. Vandekieft (2001) stated that the skill of revealing the diagnosis has been largely targeted at medical personnel, mainly because they are the group who usually bring together all the results of investigations to arrive at diagnosis, treatment plan and prognosis. That could be the reason for majority of 65%

caretakers doctors themselves revealed the diagnosis. But because of various constraints a medical doctor cannot initiate ventilation of caretakers which highlights the potential need for Medical Social Workers to work with caretakers and patients immediately after the diagnosis.

As cancer is terminal illness in many cases, it is extremely challenging to health care professionals to disclose the diagnosis. Cancer being traumatic in nature can result in apprehension, hassle, and despair to patient, spouse and entire family members. For Chaturvedi (2012) breaking bad news is a skill, in which many doctors and health professionals are poor. He proposed the concept of psychiatric Oncology, related to psychological and emotional challenges of both patients and care givers. It is also related to the development and outcome of cancer. Life threatening diagnosis of cancer itself induces psychological and emotional responses. There is a need to soften the impact of reaction and encourage ventilation of emotions. Chaturvedi, Chandra and Simha (2008) suggests active listening to patient and family members as a technique to ease their stress and pain. Chaturvedi (2012) observes informational care, providing space for catharsis, answering queries, involving patient in discussion regarding treatment is psychological management while breaking bad news in Cancer care. Counselling Sessions, Cognitive Behaviour Therapy, Behaviour Therapy, Support Groups can be useful in this direction. These psychological interventions can develop positive attitude and help in coping with the initial reactions to diagnosis of cancer. Communication patterns like consistency and openness on the part of the health care professionals to discuss issues of caring and holding separate discussions with patients and care givers especially at the end of life would be more desirable (Clayton, Butow and Tattersal, 2005). But, the informational and emotional needs of both patient and care givers may vary, and hence it would be more complex task for oncologists and doctors. Trained medical counsellors can play this role more effectively.

### **Conclusion**

On the basis of the study findings, it can be said that there is a need for Medical Social Worker in oncology setting to effectively deal with the psycho social problems faced by the caretakers of persons with cancer specially beginning from revealing of diagnosis and managing the various emotions expressed. A professionally trained medical Social Worker, equipped with psycho social skills to work with caretakers, patients and their families can be a effective oncology Social Worker

Multidisciplinary approach in cancer care is the need of the hour. It can build a proper support mechanism for the person suffering from cancer and his family.

Facilitating effective communication between person with cancer and caretaker; caretaker and medical personnel; caretaker and other family members will be the significant task. The most important implication of the current study is the unveiling of the need for medical Social Workers in Oncology settings and the interventions they can deliver.

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