



Anxiety, Stress, Depression And Fear of Death In Caregivers Of Cancer Patients Of Stage Three And Four Undergoing Chemotherapy

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Abstract

Caregivers have a very crucial role to play when it comes to the treatment and management of a cancer patient's life. The caregivers too are affected by the trauma of their patient, more so when the caregiver is a family member of the patient. In India, especially in the middle and low income group population the role of the primary care giver is that of a family member. As such their well-being is closely associated with that of their patient. The caregiver is not only for the physical support, but emotionally and psychologically attached to the patient and both the patient and the caregiver often mirror each other's stress, fears and anxieties. The progression of cancer through the crucial stages builds up on the negative feelings related to treatment outcomes and adversely affects the caregiver. Each stage of cancer is associated with some similar and yet some different psychological effects on the caregiver. For the present study a comparative analysis was done between the anxiety, stress, depression and fear of death that caregivers experience for stage three and stage four cancer patients undergoing chemotherapy. The study was conducted on Indian caregivers of stage three and stage four cancer patients undergoing chemotherapy in the hospitals in the city of Kanpur, Uttar Pradesh. The caregivers were assessed on the psychological variable largely associated with those taking care of cancer patients which have a direct effect on their wellbeing. Interviews were also conducted to get clarity into their responses and come to conclusions related to their well-being. The study concluded that caregivers of stage three cancer patients go through high level of psychological distress due to lack of tolerance and acceptance level. For caregivers of stage three cancer patients there is still a glimmer of hope of recovery. While for caregivers of stage four patients, caregivers becomes more tolerable and realistic towards the situation and are willing to accept the inevitable reality. Psychological health is a major component of overall health both for the patient as well as the caregiver, especially for cancer patients and their caregivers. The care giver needs to work on their fear, stress, anxiety and depression to maintain their well-being and be fit enough to care for the patient and be an emotional anchor for them. For the caregiver it is a long journey ahead. Even after their role

comes to an end, their related psychological experiences can have a debilitating effect on their future health and happiness.

Keywords: Anxiety, stress, depression, fear of death, caregivers ,cancer patients

Introduction: A caregiver or informal caregiver is an unpaid and without formal training (in the related treatment) member of a person's or patient social network who helps them with activities of daily living. Caregiving is most commonly used to address impairments related to old age, disability, a disease, or a mental health. Caregivers can be health professionals, family members, friends, social workers, or members of the clergy. They are responsible for looking after another person who is sick or disabled. Although, caregivers work in the home and help their clients with daily activities, such as bathing and bathroom functions, feeding, grooming, taking medication, taking to the health professionals and some housework. They develop close ties with the day to day needs that a senior might not be able to do on their own any longer. If the caregiver is the family member some extra responsibilities are also there like taking care of other members of the family, managing professional duties for financial support, household chores etc. There are different types caregivers that provide specific care, like family caregivers can help relieve burdens and support individuals in need. They may help for a long time or just a short time, but their care is always important. Caregivers are classified as – Private duty caregiver (these are typically screened through

the agency, bonded, and insured), Independent caregivers or Private caregiver (independent caregivers do now work through an agency), Family caregiver (members of the family who choose to care for a loved one), Respite caregiver (these caregivers provides care for a period of time to give a family caregiver a break).

Cancer is one of the common health conditions for which caregiving becomes essential , especially during the later stages of the disease progression. It is perhaps the most dreaded of the diseases with more fear attached to it than awareness about treatment, treatment outcomes and care required. The mere term 'Cancer' induces immediate stress and anxiety in the patient as well as the care giver. The care givers experience a sense of vulnerability and awareness of inability to protect loved ones. Disruption is schedules and taking on new roles of care giving and other duties may put on strain. Role of care giver is very daring, it may lead to resentment if own needs are not being meet. Here wellbeing of the patient as well as the caregiver is very important because to provide good care the caregiver; specially if the caregiver is family member, needs to be physically as well as mentally strong.

Cancer is typically labelled in stages from I to IV, with IV being more serious. Most cancers that involve a tumor are staged in five broad groups. Stage 0 means there's no cancer, only abnormal cells with the potential to become cancer. This is also called Carcinoma in situ. Stage I means the cancer is small and only in one area. This is also called early -stage cancer. Stage II and III mean the cancer is larger and has grown into nearby tissues or lymph nodes. Stage IV means the cancer has spread to other parts of the body. It is also called Advanced or Metastatic Cancer.

Apart from the pharmacological interventions psychotherapy and counselling are equally required throughout the treatment process both for the patient and the caregiver. Many physical as well as psychological changes also occurs during this period which puts the patient in a highly vulnerable position along with the care giver. The care giver would not have any physical repercussion of caregiving, but the psychological distress is enormous and inevitable and could lead to disorders like anxiety, depression , phobia if the period of caregiving is prolonged and without any psychological interventions.

The purpose of the study was to compare the level of stress and anxiety in caregivers of stage three and stage four cancer patients undergoing chemotherapy. From existing studies it is concluded that caregivers also go through various psychological changes during the period of caregiving. Not only psychological but some physical changes also occur due to lots of distress and anxiety which they suffer throughout care taking period. It has been seen that there is very less focus on caregivers, generally all focus is on patient. It is necessary to focus on caregivers as well. So, that they could take care of themselves as well as patient properly. In Indian scenario it has be seen that usually the caregiver is women , as she has other responsibilities also like a mother, daughter, wife etc which lead to self-neglection. The researcher chose this study as she also has gone through that period and being a caregiver for her mother, she has gone through both psychological as well as physical distress. There is lack of awareness in the society regarding various mental health facilities and its importance. The researcher was also interested in knowing the differences that existed in the prime psychological states associated with the treatment and treatment outcomes and death.

The existing studies on caregivers as well as cancer patients found that there is prevalence of psychiatric conditions in cancer patients as well as their caregivers going through treatment various psychiatric conditions such as depression, anxiety, panic disorder etc also occur or comorbid in cancer patients, (Alexander Dinesh & Vidya Sagar (1986). Although, younger patients and those with early phase of cancer shows higher death anxiety. As there is guilt of not achieving their goals and not enjoying phases of there of life. It is concluded that younger patients as well as their caregivers suffers from high death anxiety. (Firoz & Beg 1987) while in Indian scenario it has be seen that younger patients with early phase shows high death anxiety and there is lack of scope of cancer prevention and early detection programs in India. There is lack of awareness regarding cancer treatment and stigma is attached in the society regarding cancer as deadly disease. There is alarming rate of depression in cancer caregivers, which is comparable to or even higher than in patients themselves. Depression is common among caregivers of patients with breast cancer, there is need for focused interventions for this group, which may improve the outcome of patient as well (Sreeja Sahadevan, Vasudevan Namboodiri (2019). The quality of life of caregivers as well as cancer patients is highly influenced during the period of chemotherapy and is often under reported. Interventions that can improve health related quality of life, especially in the domain of mental health for both cancer patients and caregivers, need to be implemented. (Konstantinos Kamposioras, 2012). Along with the treatment and after treatment there is need to understand more about the effects of cancer on diverse aspects of quality of life of family members. (American Cancer Society, 2002). Caregiving is not an easy task, palliative caregiving is stressful, challenging and can impact the caregiver's physical, emotional, psychological and social wellbeing. It is important for health professionals

to improve the support, guidance and education given to the caregivers of cancer patients on palliative care. (Lovely Antony, Linu Sara George, Tessa Tressa Jose (2018). There is huge burden on caregivers they also go through various stressful situations during caregiving and there is need of more awareness and use of technology to support informal cancer patient caregivers. (Erin E. Kent, Julia H. Rowland, and Karen Huss (2015)). In society the burden of caregiving is poorly understood, the substantial burden on family caregivers coupled with lack of adequate number of cancer hospitals, there is public health imperative to recognize the important group. It is very important to sensitized all level of health staff in cancer hospitals regarding burdens faced by family caregivers. (S Likhmana, SK Bhasin, P Chhabra, MS Bhatia ,2010). There are substantial gaps in knowledge regarding a range of health technologies that facilitate family caregiver support and it is distribute onto health institutions. (Ji Youn Shin, Tammy I. Kang, Robert B Noll, Sung Won Choi ,2017).

Methods: The objective of the study was to assess stress, depression, anxiety, fear of death in Indian caregivers of stage three and stage four cancer patients undergoing chemotherapy; to find there existed a difference in the experience of these psychological states between the caregivers of the two set of cancer patients and the possible correlation between them. It was hypothesised that H1: stress, anxiety and fear of death would be significantly high in caregivers of stage three cancer patients undergoing chemotherapy than the care givers of stage four cancer patients; H2: Stress will be the same for both caregivers of stage three cancer patients and caregivers of stage four cancer patients undergoing chemotherapy; H3: There will be a positive correlation between all the psychological variables, stress, anxiety, depression and fear of death.

The present study followed an expo- facto research design. Out of the 106 caregivers contacted, final data was collected from 60 caregivers, of which 30 were caregivers of stage three cancer patients and 30 caregivers of stage four cancer patients. All patients were undergoing chemotherapy and all care givers were adult caregivers of the age 30 years and above. Data was collected from the caregivers who were coming to the cancer specialist hospitals in the city of Kanpur, Uttar Pradesh, India; for the chemotherapy of the patients. All caregivers were primary caregivers and were family members of the patient. The Thanophobia scale (Joseph Merrill , and the DASS 21(Lovibond and Lovibond, 1995) were translated in Hindi using the recommended two backward translation by certified translators and psychology experts. Purposive sampling was done. Each responded was approached by the researcher individually, purpose of research was told and consent for participation taken. Full confidentiality of information shared and responses were maintained. The respondents took approximately thirty minutes to complete the questionnaire. The questionnaire were scored, tabulated for analysis to be done. Basic statistics, t- test and correlation were calculated.

Results:

Comparative Analysis

t- test was used for the analysis. The quantitative data analysis reveals that the difference of fear of death in the caregivers of stage 3 & 4 cancer patients is considered not to be statistically significant. The mean of fear of death stage 3 minus fear of death stage 4 is 2.50, that is -0.86 to 5.86, the two tailed p value is 0.1422. standard error of difference is 1.680.

Table 1 – Mean Score Comparison For Fear of Death

Group	Fear of death in caregivers of stage 3 cancer patients	Fear of death caregivers of stage 4 cancer patients
Mean	32.53	30.03
SD	6.60	6.41
SEM	1.21	1.17
N	30	30

The Quantitative data analysis reveals the difference of anxiety in caregivers of stage 3 & 4 cancer patients is considered to be statistically significant. The two tailed P value is 0.0262, the mean of anxiety in stage 3 minus anxiety in stage 4 is 4.00, the confidence interval of this difference: from 0.49 to 7.51. standard error of difference is 1.753.

Table 2- Mean Score Comparison For Anxiety

Group	Anxiety in caregivers of stage 3 cancer patients	Anxiety in caregivers of stage 4 cancer patients
Mean	15.13	11.13
SD	6.62	6.96
SEM	1.21	1.27
N	30	30

The two tailed P value of caregivers of stage 3 & 4 cancer patients is 0.0883, this difference is considered to be not quite statistically significant. The mean of stress in stage 3 and stage 4 is equals to 4.00, confidence interval of this difference: from -0.62 to 8.62. standard error difference is 2.307.

Table 3- Mean Score Comparison For Stress

Group	Stress in caregivers of stage 3 cancer patients	Stress in caregivers of stage 4 cancer patients
Mean	15.60	11.60
SD	10.51	7.02
SEM	1.92	1.28
N	30	30

The two tailed P value of caregivers of stage 3 & 4 cancer patients is 0.0678, by conventional criteria this difference is considered to be not quite statistically significant. The mean of depression in stage 3 and stage 4 is -3.07 confidence interval of this difference: from -6.36 to 0.23. standard error of difference is 1.647.

Table 4- Mean Score Comparison For Depression

Group	Depression in caregivers of stage 3 cancer patients	Depression in caregivers of stage 4 cancer patients
Mean	12.07	15.13
SD	6.51	6.25
SEM	1.19	1.14
N	30	30

Correlational Analysis

A. For Caregivers of Stage Three Cancer Patients undergoing Chemotherapy

The stage wise correlation between the variables reveals that the relationship between depression and stress is strong positive, the value of R is 0.9423, which means depression increases with stress, these both are directly proportional to each other therefore increase in one variable results increase in other variable. The value of R² (coefficient of determination) is 0.8879, (Table 1). The correlation between depression and anxiety of caregivers of stage three patients reveals that, the value of R is 0.5083, this is considered as moderate positive correlation, which means that depression increases with increase in anxiety. The value of R² coefficient of determination is 0.2584,

(Table 2). The correlation between fear of death and depression in caregivers of stage 3 is positive but relationship is weak between these two variables. The value of R is 0.0948, and the value of R² is 0.009. it reveals that the level of depression increases with increase in fear of death of the loved ones and vice- versa, (Table 3). The correlation between stress and fear of death in caregivers of stage three patients is positive, the relationship between the variables is weak. The value of R is 0.2874 and the value of R² is 0.0826, which means that change in the level of stress influences the fear of death of caregiver and vice- versa, (Table 4). The correlation between anxiety and fear of death is positive, the relationship is weak, R is 0.0488 and R² is 0.0024. it reveals that increase in anxiety causes increase in fear of death and vice- versa, (Table 5). The relationship between stress and anxiety in stage three caregivers is moderate positive, which means there is a tendency for high one variable scores go with high another variable scores and vice- versa. The value of R is 0.6673 and R² is 0.4453, (Table 6).

Correlation Between the Psychological Variables for Caregivers of Stage Three Cancer Patients

TABLE 1	TABLE 2	TABLE 3	TABLE 4	TABLE 5	TABLE 6
X values	X values	X values	X values	X values	X values
$\Sigma = 362$	$\Sigma = 350$	$\Sigma = 350$	$\Sigma = 468$	$\Sigma = 454$	$\Sigma = 454$
Mean = 12.067	Mean = 11.667	Mean = 11.667	Mean = 15.6	Mean = 15.133	Mean = 15.133
Deviation square = 1227.867	Deviation square = 1080.667	Deviation square = 1080.667	Deviation square = 3203.2	Deviation square = 1269.467	Deviation square = 1269.467
Y values	Y values	Y values	Y values	Y values	Y values
$\Sigma = 468$	$\Sigma = 454$	$\Sigma = 966$	$\Sigma = 966$	$\Sigma = 976$	$\Sigma = 468$
Mean = 15.6	Mean = 15.133	Mean = 32.2	Mean = 32.2	Mean = 32.533	Mean = 15.6
Deviation square = 3203.2	Deviation square = 1269.467	Deviation square = 1290.8	Deviation square = 584.4	Deviation square = 1263.467	Deviation square = 3203.2
R = 0.9423	R = 0.5083	R = 0.0948	R = 0.2874	R = 0.0488	R = 0.6673

B. For Caregivers of Stage Four Cancer Patients undergoing Chemotherapy

The stage wise correlation between the variables reveals that there is positive correlation between depression and stress in caregivers of stage 4 cancer patients. The relationship between the variables is weak. The value of R is 0.2331 and value of R^2 is 0.0543, (Table 1). The relationship between stress and anxiety in stage 4 is positively correlated and the relationship between the variables is weak. The value of R is 0.0379 and R^2 is 0.0014. therefore, stress and anxiety are interrelated increase in one causes change in another and vice versa, (Table 2). The correlation between depression and anxiety is positively correlated, the value of R is 0.2331 and R^2 is 0.0543, (Table 3). The relationship between depression and fear of death is negatively correlated and the relationship between the variables is only weak, the value of R is -0.2848 and R^2 is 0.0811, (Table 4). Stress and fear of death in stage 4 is negatively correlated and the relationship between the variables is weak. The value of R is -0.3721 and R^2 is 0.1385, (Table 5). The other two variables anxiety and fear of death in stage 4 is negatively correlated, the relationship between the variables is only weak. The value of R is -0.1368 and R^2 is 0.0187, (Table 6).

Correlation Between the Psychological Variables for Caregivers of Stage Three Cancer Patients

TABLE 1	TABLE 2	TABLE 3	TABLE 4	TABLE 5	TABLE 6
X values	X values	X values	X values	X values	X values
$\Sigma = 454$	$\Sigma = 326$	$\Sigma = 454$	$\Sigma = 454$	$\Sigma = 330$	$\Sigma = 326$
Mean = 15.133	Mean = 10.867	Mean = 15.133	Mean = 15.133	Mean = 11	Mean = 10.867
Deviation square = 1133.467	Deviation square = 1277.467	Deviation square = 1133.467	Deviation square = 1133.467	Deviation square = 1366	Deviation square = 1277.467
Y values	Y values	Y values	Y values	Y values	Y values
$\Sigma = 330$	$\Sigma = 330$	$\Sigma = 330$	$\Sigma = 901$	$\Sigma = 901$	$\Sigma = 901$
Mean = 11	Mean = 11	Mean = 11	Mean = 30.033	Mean = 30.033	Mean = 30.033
Deviation square = 1366	Deviation square = 1366	Deviation square = 1366	Deviation square = 1192.967	Deviation square = 1192.967	Deviation square = 1192.967
R = 0.2331	R = 0.0379	R = 0.2331	R = -0.2848	R = -0.3721	R = -0.1368

Discussion: The role of the caregiver is not an easy role. Along with the progression of the patient's disease, the psychological state of the caregiver undergoes changes, most often in a detrimental way if not managed well in time. The average mean scores of depression, anxiety, stress indicate that a caregiver experiences them during his caregiving tenure, making him or her susceptible to psychiatric disorders. The caregivers of stage three cancer patients suffer from high level of depression due to the stress they face in their day to day life. Depression and stress both are psychological changes which occurs due to imbalance in coping mechanism. Depression is a persistent feeling of hopelessness and sadness and lose interest in activities of day to day life and affects social, functional, occupational and personal life of an individual, (DSM5). While stress is a feeling of emotional or physical tension. It can come from any event

or thought that makes an individual feel frustrated, angry, or nervous. It is bodily reaction to a challenge or demand, (Medlineplus, May 2018). As the life of caregiver is highly affected in the period of caregiving which may lead to imbalance in their lifestyle, studies, appetite, sleep pattern, finance, occupational and personal life etc. these changes further lead to tension regarding their future and causes anxiety. However, there is biological reason behind it, during stress hormone such as cortisol which is also known as "stress hormone" is released which reduces serotonin, dopamine and other neurotransmitters in the brain, which has been linked to depression. In both caregivers of stage three and four cancer patients the level of stress, depression and anxiety is high and they all are positively correlated with each other. It reveals that change in any one of them influences the others and vice versa. Although, the fear of death in caregivers of cancer patients of stage three going through chemotherapy is positively correlated with depression and anxiety in stage three. It reveals that anxiety

regarding future due to imbalance in various aspects of life and negative outcomes regarding the health of the patient causes feeling of worthlessness and sadness which may further lead to depression and influences thought pattern, tolerance and acceptance level of the caregiver. But still there is a hope that the patient is still in the third stage, there is chance of some recovery and if something unfavourable happens to the patient then it causes fear of death in caregivers. While in stage four, the caregivers become more tolerant to the situation and are aware of the reality, as the patient is in stage four there are very less chances or no chances of recovery (metastasise) so they become more realistic, accept the reality and prepare themselves for the stage of termination. On the basis of existing studies it has been seen that from the period of diagnosis the level of psychological changes increases but by reaching the transitory phase the level of psychological changes slow down. Therefore, there is need to focus on caregivers as well during the period of caregiving and after the phase of termination. There is need of counselling and psychological interventions for patient, caregiver as well as family members also.

Conclusion: On the basis of the findings it can thus be concluded that the caregivers of stage three cancer patients going through chemotherapy go through high level of stress, depression, anxiety and fear of death. As the patient is still in stage three for the caregiver there is still a hope of some. But during this time if something unfavourable happens to the patient it causes increased distress and fear of death of the loved one. For caregivers of stage four cancer they are by this time aware that there are very less or no chances of recovery. So, the caregivers become more realistic and accept the reality. Though this awareness is there yet it does not decrease the stress as by this time imbalances in various aspects of their life and the inevitability of the unfortunate end creates more stress. There is also a sense of despair that despite all efforts, the wishful outcome could not be achieved. It is easy to understand the prognosis of a disease but difficult to come to terms with it and manage one's life accordingly. The study corroborates that for caregivers their psychological distress goes not lessen knowing the inevitable and that stress, depression, fear of death anxiety remain all through varying in their severity. This makes it important for us to work on the well-being of caregivers and come up with different interventions for the different stages of progression of their patient's illness so they stay strong and mentally healthy right from the time they get to know of their role. Further research on specific factors affecting the well-being and areas for training, counselling and skill enhancement need to be identified. This has far-reaching implications specially for the caregivers who are the family members of the patient and are not trained for this role as is the case with majority of the caregivers in India. The researcher while conducting the research was not able to collect more data and also include the phenomenological experiences of the caregivers as originally planned due to the pandemic restrictions, which would have enriched the current research.

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