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Caregiver Distress in Cancer

Anshika Arora

Abstract

Cancer is a chronic disease with associated physical, emotional, social, financial and spiritual problems. The primary caregiver takes care of all these cancer-related issues for the patient. In India, usually a family member or loved one is the caregiver of the patient. The caregivers themselves feel distress and many factors may be associated with their psychological well-being. Pattern of distress may vary according to phases of the disease like at diagnosis, during ongoing oncological treatment, recovery period, remission period, recurrence of cancer, during end of life care and bereavement. Identifying and understanding caregiver distress is the first step. Active listening and good communication is important to unearth the real concerns and fears in order to relieve the distress. This chapter covers components of caregiver distress, assessment, physical, psychosocial and spiritual factors associated with distress and its management. Lastly, some recent literature related to prevalence and factors associated with caregiver distress.

Keywords: caregiver distress, cancer, palliative care, psychological distress, good death

1. Introduction

The incidence and prevalence of cancer has been increasing in developing countries in the last few decades. Cancer is viewed increasingly as a chronic disease, with prolonged management and increased rates of survival, leading to long term care requirements of the patient. In developing countries like India, the primary caregiver for long-term and intensive care of a cancer patient is preferably the family member, and sometimes family member is the 'only option' available to the patient as caregiver. The caregiver is usually a close relative like parent, child, sibling, spouse or a friend. This person usually has a deep relationship with the patient and more importantly, a significant emotional co-dependence. Cancer diagnosis and treatment not only affects patients but also their family, resulting in psychological distress.

In cancer treatment, there has been a shift from in-patient care to ambulatory and out-patient care. This increases demands on the patient's caregiver towards unmet physical, psychosocial and spiritual needs of the patient. Most of the caregivers have little preparation or training to take up this role. With newer modalities of treatment, cancer patients have prolonged survival through all stages of disease, making it more of a chronic disease. These trends have definitely increased the caregiver burden. The act of caring for a sick patient is multifaceted. The caregiver needs to have dedicated time to take the patient for hospital appointments and care for disease and treatment related problems at home as well. The caregiver then may face loss of personal work due to lack of time. They may eventually develop varying

degrees of emotional and psychosocial distress. There is ample literature on the palliative care needs of cancer patients. However, there is limited literature on the psychosocial needs of the relatives or caregivers of cancer patients. A significant proportion of caregivers have unmet needs for emotional support. They may have unaddressed fears regarding the patient’s prognosis, disease related information and treatment details. Furthermore, caregivers of patients with advanced disease usually have distress symptoms like anxiety and depression. Caregivers face extreme demands right through the course of the cancer, survivorship and also during bereavement.

2. Components of caregiver distress

The common psychological distress problems would be- anxiety and anxiety disorders, low mood and depressive disorders and adjustment disorders (Table 1).

Whenever a person perceives threat, ‘anxiety’ is the natural response. This response helps to enhance their actions in order to take care of the threat. When does this natural response of anxiety become a problem? Either the threat is out of person’s capability to resolve, or the anxiety hampers with the person’s ability to act appropriately in the situation. So, ‘anxiety’ may be seen as a spectrum between normal response to persistent to severe anxiety (Figure 1).

Some people experience anxiety in response to day to day stressors lifelong, for them anxiety due to caring for someone’s cancer is just another symptom of their own chronic anxiety problem. This may be seen more as ‘chronic anxiety’. On the other hand, some people may experience ‘acute anxiety’. It is generally a temporary response to a particular stressor, for example, being delivered the news of metastatic and incurable cancer in the patient, or the news of recurrent cancer. In a caregiver, anxiety may be related to –

- caring for a patient with uncontrolled symptoms like, pain or dyspnoea,
- fear of unknown like, prognosis of the patient,
- anticipation of symptoms post treatment like, chemotherapy induced nausea and vomiting,
- lack of sleep, either due to distress, or caring for the patient at night continuously,
- fear of being left alone after the death of the patient, etc.

Some people may be suffering from anxiety disorders like- panic disorder, generalized anxiety disorder and mixed anxiety and depressive disorder. It is commonly seen that people with symptoms of anxiety usually have adjustment disorder or varying degrees of depression.

1	Anxiety and anxiety disorders
2	Low mood and depressive disorders
3	Adjustment disorders

Table 1.
Components of caregiver distress.

Figure 1.
This figure shows the spectrum of caregiver's response to the perceived threat posed by cancer in their loved one.

Caregivers suffer from low mood very often. 'Depression' is a common occurrence in cancer patients, and is also common in their caregivers. There is a spectrum of mood disorders ranging from sadness to adjustment disorder to depression. Depression is not the same as feeling sad. The common features seen in depression are- inability to experience pleasure (anhedonia), helplessness, hopelessness, feelings of loss and a flattening of all feelings. They may feel irritable, worthless; there may be lack of interest in daily activities or recreational activities; suicidal ideation is important to look for. There may be physical features like lack of sleep, weight loss, fatigue, reduced energy level and lethargy. Depressive disorders are usually under diagnosed in caregivers. This results from lack of active screening, lack of focus on the caregiver, more focus on the cancer patient, social cover-up by the caregiver and other simultaneous psychiatric problems like anxiety.

There will be many people with distress, who do not fall into the diagnostic criteria for depression or anxiety if the diagnostic criteria are applied strictly. These people may have 'adjustment disorders'. The main components of adjustment disorders are- they occur in response to a stressor, they usually last for a short duration of time (acute in nature), there will be emotional turmoil and distress and finally this results in function impairment. The diagnosis of adjustment disorder is more of a clinical judgment. The main temporality to remember is that the distress should start within 1–3 months of the stressor and be relieved within 6 months of resolution of the stressor. It is important to acknowledge adjustment disorders if distress is recognized in the caregiver, because otherwise, they may be inappropriately diagnosed to be depressed and prescribed unnecessary medications.

3. Assessment of caregiver distress

It has been seen in cancer patients, that regular and ongoing *evaluation* of psychological distress improves the management and treatment of psychiatric issues. This eventually contributes to better outcome, patient satisfaction, doctor-patient partnership, and improved overall care [1]. This is true even for caregiver distress. Regular screening and ongoing evaluation is as important aspect for good quality of life in the patients and their caregivers. Distress is defined as

“a multifactorial unpleasant emotional experience of a psychological, social or spiritual nature that interferes with coping.”

There are various tools and scales to screen for distress. Definitions for specific mental disorders are provided in Psychiatric Association's *Diagnostic and Statistical*

Manual (DSM-5) [2]. A visual analog tool, the distress thermometer, is used as a self-report method to screen and measure distress. This tool has been validated against other tools used to screen for psychological distress [3]. *Distress thermometer* is an invaluable tool to screen for psychological distress. It has two components; one is a visual analogue scale ranging from 0 to 10. Zero being no distress and 10 being extreme distress. The second component asks the person to answer a series of yes or no questions pertaining to- practical problems, family problems, emotional problems, spiritual/religious problems and physical problems. This scale measures the global distress score, the list of problems are then used to identify areas that need focused care. The *Hospital Anxiety and Depression Scale* is self administered 14 question scale. This validated tool can be used to screen caregivers for anxiety and depression. A score from 0 to 21 is generated for both anxiety and depression, 0–7 indicates normal, 8–10 borderline and 11–21 abnormal score. People with abnormal score can then be reviewed in detail for anxiety and depression. Another tool useful for depression is *Beck Depression Inventory* (BDI). BDI is a self reporting, 21-item rating tool. It measures attitudes and the symptoms of depression. A shorter version with 13 items is called BDI-II. It has an internal consistency of 0.73 to 0.92. For anxiety, *Beck Anxiety Inventory* (BAI) tool can be used. It again consists of 21 items and is a self reporting rating questionnaire. Instrument *General Health Questionnaire* (GHQ-12) is a validated tool to assess the severity of any mental problem a person may have suffered from in the past few weeks. This instrument consists of 12 items, 4-point scale, with total score ranging from 0 to 36. A higher score indicates a worse mental problem. *Psycho-Oncology Screening* is a screening tool, specific for cancer. The screening is based on 5 to 10 minutes of standardized interview, which comprises of

- questions related to socio-demographic characteristics,
- questions related to medical characteristics, and
- questions on the subjective experience associated with psychological distress in the past 3 days

To assess the third point, Psycho-Oncology Screening tool uses 6 items, rated from 0 to 4. Any patient with >9 points on this rating scale is considered distressed. Another validated, self administered tool is the *Psychological Distress Inventory*, used to measure distress in cancer patients. *Mental Health Quotient* is an online assessment tool. It captures the complete mental profile of an individual, ranging from “Clinical to Thriving”. Another useful tool to screen for distress and unmet needs of a person is *Needs Evaluation Questionnaire* (NEQ). It is again a self-administered tool, with 23 items with dichotomous answers. The *Kessler Psychological Distress Scale* (K 10) comprises of 10 items with scores ranging from 1 to 5 for each item (minimum possible score 10, maximum score 50). The grading is done as per following cut-offs

- 10–19 Likely to be well
- 20–24 Likely to have a mild disorder
- 25–29 Likely to have a moderate disorder
- 30–50 Likely to have a severe disorder

4. Physical factors affecting caregiver distress

Patients with advanced cancer usually have multiple physical symptoms, with varying degrees of severity. In addition to this, the symptoms burden is dynamic, i.e., ever changing in severity and pattern, as the disease profile changes. The **Table 2** shows the prevalence of common physical symptoms in an advanced cancer patient.

The caregiver of an advanced cancer has to be able to care for above symptoms. Seeing your loved one in pain or with anorexia can be a source of distress, caring for someone with dyspnea can be quite scary and cause a lot of distress in the caregiver. Due to fatigue, patients with terminal cancer are unable to carry out recreational or occupation activities and even sometimes activities of daily living. Their caregiver, usually a family member, is equally affected emotionally by the changes in life style the patient may have to make to adapt to constant fatigue. In an Indian study, the researcher asked about the most bothersome symptoms reported by parents of dying children. Pain (85%) and respiratory distress (73%) were the commonest [5]. Much of the fear is due to past experiences of uncontrolled symptoms. This eventually leads to anticipatory psychological distress in both patients and their caregivers. In India, many complex factors like cost, scarcity of medical facilities in remote areas, taboo, etc., contribute to reduced expert medical care opportunities and hospice care. Advanced cancer patients with smelly fungating wounds, oro-cutaneous malignant fistulas, large bed sores, bowel and bladder dysfunction are being managed primarily at home by caregivers. The caregivers have the added responsibility of taking over the nursing role, usually full time. This may leave little or no time for personal needs, being a source of distress. Consider a patient who has a colostomy due to malignant bowel obstruction, this patient will have body image issues. He may become socially recluse, irritable, depressed and feel overall limited by the colostomy bag. Seeing him in psychological pain, the patient’s caregiver and loved ones may find it distressing. So, change in body image of a patient whether due to a stoma, or amputation, or mastectomy not only affects the psyche of the patient but their family members and caregivers.

Symptom	Frequency (%)
Pain	35–96
Anorexia	30–92
Fatigue	32–90
Delirium	6–93
Dyspnoea	10–70
Depression	3–77

Table 2.
Prevalence of common symptoms in patients with advanced cancer. [4].

5. Psychosocial factors affecting caregiver distress

Being diagnosed with cancer is a life-altering event in a patient’s life. Nature of his/her response to diagnosis, treatment etc. will impact mood of the patient and quality of the social support. Managing strong emotional responses will affect patient’s family and vocational exchanges. Similar points could be envisioned for

the caregiver. In a country like India, the caregiver, usually a close family member is the first to receive the news of diagnosis of cancer; even before the patient. During this early period of breaking bad news and details of disease related prognosis, the caregiver goes through psychological problems like- acute stress disorder. Usually, the person may go through phases of disbelief, fear, anxiety, in-ability to sleep, blame, anger and intrusive thinking etc. Now, their lifestyle may never remain the same. They go from the routine activities to a whirlwind of hospital appointments, tests, investigations and consultation with multiple doctors. Consolidating all the information shared with them regarding the disease and treatment during these consultations and then, the mammoth responsibility of taking the right decisions can be quite daunting. The caregivers could quickly move from acute stress to more chronic post-traumatic stress disorder [6–8]. During the stage of active treatment of cancer the caregiver may experience exhaustion, helplessness and disruption of social roles. As the treatment ends and follow up period starts, there may be fears of disease recurrence, long-term treatment side effects, higher vulnerability and sudden isolation. In India, another important factor to consider is feeling of *taboo*. Generally, people fear that if the society comes to know that their family member has cancer, the family will be socially isolated, to the extent that they may be considered bad luck to be around. The constant effort to keep the secret of cancer in the family is a cause of distress. *Collusion* is another important consideration in context of India. The primary caregiver keeps the knowledge of diagnosis or the knowledge of disease prognosis to themselves. They hardly allow the medical team to disclose cancer diagnosis to the patient in order to protect their loved one from mental trauma and resulting distress. But this *conspiracy of silence* between the caregiver and the medical team is a source of constant psychological distress in the patient, as well as the caregiver. The psychodynamics of the family is any way disturbed by the diagnosis of cancer in a family member. Adding on that, the pressure of hiding diagnosis from the patient, all while struggling through diagnostic tests and treatment of cancer will generate stress and tension for the caregivers. Collusion also blocks honest discussions among the family members and preparation for parting. Caregivers may have mixed states and degrees of depression, anxiety, psychological distress; they may find it difficulty in falling asleep or staying asleep. All these affect their quality of life. Collusion, if not resolved is a source of immense distress to family members during bereavement period too.

6. Spiritual factors affecting caregiver distress

Spirituality is about valuing the non-material aspects of life, it is also concerned intimately with day to day reality. “Spirituality can be defined as *awareness of the transcendent*, the awareness of something beyond ordinary human knowledge or experience” [9]. It concerns with the whole life. The *4S model* of a human being involves- the ‘soma’ (physical), social, psychological dimensions; embraced and enhanced by the spiritual dimension. Relationship with the ultimate reality, meaning of life, purpose of living, deeper meaning behind experiences and harmony with other beings and the universe are some aspects spiritually is concerned with. Religion is a shared system of beliefs and certain rituals. One’s spirituality may be either independent or dependent on their religious believes. Whether one calls it spirituality or soul or ‘*atma*’ or the spirit, it is about exploring and discovering the meaning or purpose of one’s identity and life.

Dealing with major life-stressors, like diagnosis and treatment of cancer, has been shown to trigger post-traumatic growth in the patients and their caregivers. There may be an altered perspective on what really matters in life, what is the

meaning behind life [10]. The higher domains like life appreciation, relating to other's problems, empathy, compassion and spiritual matters are seen to be affected in patients and their families [11, 12].

The following are some of the spiritual needs of a caregiver-

- *Guilt or Shame* Person feels they are reaping the results of their past actions. They are being punished for their ill actions by suffering like this. They feel that they deserve this misery and do not deserve any better. The concept of 'karma'.
- *Intense suffering* Receiving bad news, long periods of caring for a cancer patient can lead to isolation, loneliness and vulnerability. This intense suffering may overwhelm the caregiver into feelings of suicide.
- *Sense of -lessness* Caregivers may develop feelings of helplessness, hopelessness and meaninglessness. Some people are able to cope with this, but others may become withdrawn and depressed. They may feel - 'What's the point of going on if it's going to be like this?'
- *Breaking up with God* Some may question God and other religious authorities- "Why us, what did we do to deserve this?" and feel angry. Others may just break their ties with God and the religious believes they had been following till now. For some, their relationship with God may change- "Now I can't ask for help from God and talk to Him the same way."
- *Premature stoicism* Stoicism is defined as- "the endurance of pain or hardship without the display of feelings and without complaint." In Indian culture, the family members and loved ones feel this overpowering need to take care of their cancer patient. The caregiver often feels that he or she cannot let down their patient and thus feel they have to do it all. They also endure suffering, without complaining, as part of this duty towards the family member.
- *Nightmares* Each one of us may have had that vivid dream about falling endlessly or being stuck in a box and unable to get out, at some point of time in our lives. Cancer caregivers, if asked, share that they frequently get these nightmares.

Thus, the interplay of elements like experiences, values, beliefs, relationships, assumptions, motivation, dreams, aspirations, thoughts and emotions determines the spiritual health or *qualify of spiritual health*.

7. How can one help

Medical professionals and health team may be able to reduce caregiver distress related to cancer if it is identified early and adequate steps are taken to relieve the causes of distress. Also, they can work with caregivers to help them attain something of emotional significance from the experience of loss or suffering [13]. Cancer patient caregivers will benefit from improving their *coping skills* and learning more adaptive coping skills (**Table 3**). They need to preserve their emotional balance, sense of know-how, sustain social relationships and above all, be prepared for the uncertain future. Expression of emotions to social support system is shown to improve optimism and reduce distress in cancer patients [14–16]. Similar strategies

Improving coping skills
Learning adaptive skills
Group psychotherapy
Good communication

Table 3.
Proposed interventions to relieve caregiver distress.

aimed at increasing the social support for caregiver may be desirable. *Adaptive coping*, in terms of emotion focused and problem focused, may help the caregiver to match their response to a difficult medical situation. Avoidant strategies may not be that adaptive and useful in the long run [17, 18]. The components of adaptive coping are- facing not fleeing, altering the perception, coping actively, social support and expressing emotion. The caregiver of a terminally ill cancer patient needs to be able to cope with uncertainty of eminent death. Usually they are anxious to know the ‘time left with the patient’. It is good to ask the caregiver that why they wanted to know in the first place. They may express a particular concern, like, the wedding of a loved one or travel plans. This opens a forum for discussion and scope for addressing the real concerns. Acknowledging that living with this kind of uncertainty is in fact difficult for most people will help the caregiver to get some perspective. Lastly, discuss certain coping strategies like living only one day at a time, living and planning till the next event like a birthday, learning to hope for the best but be prepared for the worst.

Group psychotherapy has already been shown to be efficient in providing psychological support to cancer patients [19, 20]. The same concepts could be applied to support cancer caregivers. The components of group therapy include- social support, emotional expression, demystifying dying, living in the present and re-organizing life priorities, family support enhancement and effective communication with medical team.

Good communication skills on the part of the medical team are a starting point for identification of distress in the cancer caregivers. A good approach would be to identify not just the telltale signs and symptoms of distress (like depression), but identify all psychological issues relevant to the caregiver at that moment. The person may be in a phase of denial or anger or disbelief or sadness. Identifying these and working on the core issue may serve better to take care of psychological distress. For example, if a cancer caregiver has received news of cancer recurrence in the patient, he may be in ‘denial’ for some time. This is a usual response when one is unable to deal with the weight of the reality and looks for alternate explanations. The ‘denial’ may result in anxiety. Rather than treating the anxiety with drugs, addressing the core issue, which was ‘denial’ in this case, acknowledging its effect on the person and an open honest discussion may be a better path to take. In addition to verbal communication, an effective way of conveying the message is ‘non-verbal cues’. These include things like eye contact, facial expression, act of sitting with the person, posture, placement of hands, pace of voice, voice pitch and touch. For effective communication ‘privacy’ is equally important. The person should feel safe and confident to share their emotions and thoughts. Another important aspect is not to hurry up the conversation, we have to create the illusion of ‘time’ and should not interrupt as far as possible. Lastly, ‘avoiding medical jargon’ will allow for a smoother conversation and better understanding on the part of the caregiver. Nodding from time to time, reflective questioning, picking up cues from caregiver’s statements, asking and validating their feelings, picking up non-verbal cues and finally summarizing the contents of the whole conversation are part of *active*

listening. Active listening will help finding out about caregiver's emotions, feelings and concerns. Asking 'open questions' is better than asking leading or closed questions if you want to understand their feelings and concerns.

Leading question- *Are not you feeling less anxious today?*

Closed question- *Do you feel anxious today?*

Open question- *How is your anxiety today?*

What worries you so?

How do you think you feel today as compared to our previous consultation?

Next important thing to remember as a medical professional is to not use 'distancing behaviors'. Non-verbal cues like facial expression, looking very busy and tone of voice; labeling a patient, e.g., 'she is cancer colon patient; lecturing, criticizing, making threats, issuing orders, addressing only the physical problems, using closed questions, inappropriate humor and normalising prematurely are examples of distancing behaviors.

7.1 Management of anxiety

The first step is impeccable assessment keeping the following components in mind. Firstly, look for the common features of anxiety like- vigilance, scanning, autonomic hyperactivity, increased motor tension and excessive worrying. Secondly, we need to assess the character of anxiety, whether it is acute or chronic in nature, whether it is part of a psychiatric syndrome. Thirdly, there may be some features leading to anxiety, which may be reversible. For example, the patient's symptom control could be better or the medical team could address anxiety resulting from fear of unknown prognosis by counseling the caregiver in depth regarding patient's cancer related prognosis. It is important to note here that, one needs to give ample time to listen to the caregiver, so the real reasons behind the anxiety could be explored. The main concerns and worries mentioned by the caregiver will be helpful in understanding the reasons behind anxiety. Just the act of sharing these concerns may result in decreased anxiety. Treatment approach could be pharmacological or non-pharmacological. The non-pharmacological options are- psychological counseling, progressive muscular relaxation and distraction. The main pharmacological management is use of benzodiazepines like- Lorazepam, Diazepam, Midazolam and Clonazepam. Medications should be used only for short period to break the cycle of anxiety; non-pharmacological approaches are the main stay of management.

7.2 Management of depression

As with management of anxiety, we assess for the reversible causative factors and try to eliminate these. Enough emphasis cannot be given to the fact, that spending time with the caregiver, active and patient listening is important to uncover the main concerns and fears. Addressing these fears and concerns, emotional and social support and counseling are the main stay of management. Tricyclic antidepressants may be used in a few instances.

7.3 Management of adjustment disorders

Psychotherapy is the main stay of treatment. The focus will be on spending enough time with the caregiver and listening to his/her concerns and fears. Thereafter, focus will shift to addressing these concerns, help them find solutions to problems that are reversible. There will be need to resolve conflicts. For example, there may be ongoing conflict due to collusion, the patient may not be aware of

the diagnosis or the prognosis. The caregiver, the patient and the medical team are bound to face conflict at multiple points of time in the management of cancer of this patient. Addressing the issues around collusion in this case will reduce distress in the caregiver. It is important to make an effort to improve communication between patient, caregiver and the medical team. The practical family issues and social issues like taboo and isolation need to be addressed to improve distress. There are formal approaches to manage adjustment disorders like- cognitive behavior therapy and problem solving therapy.

8. A good death

Caregiver of a patient who is nearing his death may feel a heightened need for reconciliation, affirmation, forgiveness and acceptance. It is important to note that *death is the not the ultimate failure*, poor quality of death and a demoralizing death is the real failure. Patient dying in a hostile environment of ICU, away from the physical and emotional support of the loved ones, is demoralizing to the family. Collusion prevents the spiritual nourishment between patient and caregiver, leading to a poor quality of death and distress in the bereavement period. *How can one achieve a 'good death'?* Taking care of physical issues like pain and dyspnoea at end of life of the cancer patient can be of great help. Patient and caregivers should have had adequate time and support to be able to accept death as a real eventuality and say a healthy 'good bye'. They should have had time to express love for each other. There should be openness to accept failures of life, forgive others and each other, reconcile with other family members. The achievements in life as an individual and as a family unit should be reviewed and acknowledged together. Lastly, the life journey as a whole may be evaluated and discussed among the family.

9. Recent literature on cancer caregiver distress

There are studies evaluating prevalence of distress in caregivers of cancer patients and its associated factors. In a study conducted on 641 Chinese adult cancer patients and their caregivers, it was found that *one-third* caregivers had experienced anxiety and depression and with similar degree. The factors that were found to affect the anxiety and depression in patient-caregiver dyads were- marital status, age, gender, level of information about disease, type of cancer and treatment, being the spouse, duration in role as caregiver, time spent daily on care giving, pre- and post-cancer family relationship and financial burden due to cancer treatment [21]. These factors associated with the caregiver distress may affect it with varying degree of severity. A review article published in 2018 found that caregiver distress was related to psycho-physiological elements like blood pressure and poor health related behaviors. Problem focused coping reduced depression and improved adjustment in this study [22].

Caring for children with cancer also leads to caregiver distress and burden. There may be some association between the child's symptoms and caregiver's distress. At the time of diagnosis, the parent of child may feel grief and severe anxiety. A study on psychological adjustment in families of 159 children with cancer found that during the first year of diagnosis the caregivers have clinically significant distress but the children are well adjusted [23]. Caregivers of 100 acute lymphoblastic leukemia children in Hyderabad (India) were enrolled in a study, which showed, that both mothers and fathers did not experience significantly different burden, however they used different coping strategies for the distress they felt [24]. Study published

in 2016 concluded that symptoms of children being treated for cancer and financial difficulty were significantly associated caregiver distress and burden [25].

In a randomized controlled trial published in *Oncologist* in 2017, 350 patients and their caregivers were randomized to either early integrated palliative care or regular oncological care. This intervention improved the total distress and depression scores, but no change in anxiety score were noted [26]. It has been frequently reported that psychological distress is substantially high in a nuclear family, so family based approach is needed and most effective in cancer care. The caregiver-patient dyad unit should be the focus of assessment and intervention [27]. In a study on 43 lung cancer patient and caregiver dyads, it was found that patient's Lung Cancer Symptom Scale scores correlated positively with caregiver distress and burden scores [28]. Another study on 91 lung cancer patients and caregiver dyads found that the burden, anxiety, depression, Quality of life of the caregivers was affected by the Quality of life of the patient and not their stage of disease [29].

A study aimed to assess the inter-relationship of patient and caregiver distress at the time of diagnosis of incurable cancer. They enrolled 350 patients and 275 family caregivers within 8 weeks of diagnosis of incurable cancer. They found that patients reported more depression and caregivers more anxiety [30]. The anxiety and depression were found to be interrelated in the patient and their caregiver with good correlation. A review article published in 2016 on caregivers of ovarian cancer patients found that with time the experience of the caregiver changes. During the first year of diagnosis of cancer there is minimal compromise in well being and Quality of life, however there is steady decline as the disease progresses [31]. In pediatric cancer patients health related quality of life of the children has been significantly related to the caregiver distress, with age of the child being a significant covariate [32].

There has been limited research on caregivers of head and neck cancer patients. This study interviewed 31 long term caregivers of head and neck cancer patients. Emotional distress was found related to – understanding of illness, fears, restrictions in lifestyle, change in body image, financial burden, co-morbidities and witnessing suffering [13].

A study looked at the bereavement outcome in relation to age of advanced cancer patients [33]. They interviewed caregivers of 199 advanced cancer patients at the time of diagnosis and shortly following death of the patient. They concluded that relatives of patients in middle age (40–59 years) had greater grief and related distress symptoms like depression during bereavement period. In contrast, the relatives of young-old patients (60–79 years) had greater distress during caring period and relief of distress during the bereavement period.

An Indian study [34] explored the association between distress and somatization in 100 cancer patients and their caregivers. They found that the depression and anxiety found in patient and their caregiver had significant correlation; the caregiver's distress significantly correlated with somatization in the patient. Thus, psychological evaluation and management of the caregiver distress is essential for well being of the cancer patient. A study looked at gender differences in 377 cancer caregivers in Albania and found that female caregiver had higher levels of distress and poorer quality of life as compared to male caregivers [35]. An interventional study randomized 65 patient-caregiver dyads to group intervention and 66 to usual care, the interventional group had better Spiritual well-being scores, caregiver Quality of life scores at short and long term [36].

Medical professionals and health team may be able to reduce caregiver distress related to cancer if it is identified early and adequate steps are taken to relieve the causes of distress. Also, they can work with caregivers to help them attain something of emotional significance from the experience of loss or suffering [13].

10. Conclusion

There are various factors that may affect caregiver distress. The demographic and geographic factors like distance of travel from home to the hospital, frequency of hospital visits, ease of public or private travel, financial issues, loss of work, level of education. Patient and disease factors like age, stage, prognosis, type of treatment, physical symptoms, presence of stoma or tubes, knowledge of prognosis. Caregiver factors like gender, age, relation to the patient, duration of care-giving, total time spent daily caring, etc. Various psychological and spiritual elements have to be considered as well. In the clinical setting, physicians and medical team do not monitor caregiver burden regularly. Distress in caregivers is usually under recognized, under reported and under treated. In India, first and second degree relatives are the primary source of care and support system for cancer patients, though simultaneously they experience considerable distress themselves.

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