

ORIGINAL ARTICLE

An Explorative Study of the Unspoken Grieving Experiences of Bereaved Family Members—An Indian Perspective

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ABSTRACT

Background: A vast majority of advanced cancer care, including palliative and end-of-life care, is provided by the family members. Loss of loved ones leads to practical, emotional and psychological distress and thereby poor quality of life.

Aim: The present study aims to explore the psycho social experiences of bereaved family members in the Indian context.

Methods: In this prospective observational qualitative study, bereaved family members were ($N = 42$) interviewed using a semi-structured in-depth interview schedule, after obtaining consent. Interviews were digitally recorded, transcribed and translated by the researcher. Manual thematic analysis was used for analysing the data collected.

Results: The thematic analysis of the transcripts revealed six key themes: Heightened distress, family expectations, emotional conflicts versus collusion, challenges during COVID pandemic, coping with self and others, and gratification from caregiving. Many family members maintained a positive outlook on the care they provided and shared effective coping strategies. However, most reported heightened distress due to the loss of their loved one and struggled with emotional expectations during the grieving process. Negative experiences with collusion and its consequences were also noted. The COVID-19 pandemic's impact, particularly in limiting access to support, was another significant challenge for many family members.

Conclusion: caregiving during illness or loss presents significant challenges, including emotional strain, family issues, and external stressors like the COVID-19 pandemic. However, caregivers often find fulfilment and develop effective coping strategies to manage these difficulties. It is essential to address both the emotional and practical aspects of caregiving, particularly during crises, to support family members throughout their journey.

1 | Background

A vast majority of advanced cancer care delivery in India is done by family members, be it in hospitals or at home from advanced home care team [1–3]. Due to the prevailing family structure, spouses (housewife/husband) act as important caregivers for their loved ones [4]. They do seek the help of other extended

family members, siblings and friends in providing spiritual and personal care [5–8]. Cancer-related death often leads to a difficult and exhausting decline in physical function, with symptoms that significantly affect a person's overall well-being [9]. The families of those who pass away frequently face overwhelming emotions, a lack of support, and feelings of depression, loss of appetite, sleep disturbances, and prolonged grief [10, 11]. The

World Health Organisation has officially recognised ‘Prolonged Grief Disorder’ (PGD) as a new condition in its international disease classification. Although the death of an older spouse is a common experience, nearly 25% of elderly spouses struggle with long-term grief or chronic depression [12]. Children and young adults who lose a parent are also at risk for mental health challenges, including depression and emotional distress (Marcussen et al. [13]). Additionally, siblings who lose a brother or sister to cancer require support as well (Nolpris & Hellstrom, 2005). Grief can stem from a variety of losses, not just the death of a loved one, including the loss of family, home, activities, or abilities. It is important to view an individual’s grieving process through the lens of their gender, age, personality, living conditions, vulnerabilities, and the specific circumstances surrounding the loss. Positive personal, situational, and practical experiences can significantly help bereaved families cope with the death of a loved one. These factors play an important role in managing grief and improving the overall quality of life for family members. However, understanding the emotional, social, and psychological struggles of the affected individuals is often difficult. The reason for this is that after the death of patients, opportunities to meet their families are limited, and after such a loss, it is rare for families to fully express or share their emotions. These feelings are often suppressed. The goal of this study is to explore and gain a deeper understanding of how the psychological and social experiences of these individuals are during their grieving process.

2 | Methods

This study was a prospective observational qualitative research aimed at understanding the experiences of bereaved family members. It took place at a bereavement support group organised by the Cancare Foundation in Chennai, India, for families who had lost loved ones to advanced cancer. The study included individuals who could speak and understand Tamil. Out of 49 family members approached between March 2023 and June 2024, 7 declined to participate. After obtaining consent, the final sample included 24 family members.

2.1 | Procedures

The socio-demographics of the bereaved family members were collected as part of the study. A semi-structured interview was then conducted, lasting over 30 min. The interview was carried out by a psycho-oncologist (researcher) specialising in onco-psychology, who had expertise in providing specialised care. The interview took place before the bereavement support group meeting began. The interview questions and cues were developed by the researcher, focussing on understanding the family members’ experiences and their coping mechanisms for dealing with various stressors (physical, emotional, and social).

2.2 | Data Analysis

Data from the interviews were digitally recorded, transcribed, and entered into Excel sheets, with validation by the researcher

for accuracy. One coder analysed the transcripts line by line, identifying key words and statements that reflected the respondents’ experiences. Codes were developed to describe these key points. Categories were compared to identify common themes, differences, and unique aspects. Continuous variables were analysed using SPSS software to measure the frequency distribution of participants’ demographics.

3 | Results

The time interval between the death of the loved one and the bereavement meeting varied among participants. The majority (33.3%) attended the meeting between 3 and 6 months after the loss, followed by 28.5% who attended within 1–3 months. The median time since death was 91 days, with a range from 10 to 515 days, indicating a wide variation in when bereaved family members sought support (Table 1).

Demographic characteristics of the bereaved family members showed that a greater proportion were female (59.5%), and most participants were between 31 and 45 years of age. In terms of relationship to the deceased, daughters and spouses (husbands or wives) constituted the majority. Income status varied, with a notable portion reporting no income or income below ₹25,000 (Table 2).

The themes that emerged in this study were highlighted and classified into six major sections, namely, (a) heightened distress; (b) What they expect as griever from the family, (c) collusion versus emotional conflicts; (d) challenges during COVID; (e) coping with self & with others and, (f) gratification with care.

3.1 | Heightened Distress

Many of the family members had positive outlook with regards to care. They had been involved in the long-term treatment with a curative intent and had made necessary treatment efforts earlier. This seemed to be a source of relief. Some of them (16 out of 42) felt guilty due to incidental, but late diagnosis. This was compounded by the fact that curative treatment options were limited and they had resorted to palliation at the outset. They were unable to overcome their grief; and this is on the rise.

3.1.1 | One-Woman Griever Reported

■ We led a happy life until my husband was diagnosed with cancer; having to go to the doctor for a sudden

TABLE 1 | Time since death of the loved one to Bereavement meet
Time since death to the meet.

(Months)	No of patients	Median (range)
> 1 month	7 (16.66)	
Above 1–3 months	12 (28.5)	
Above 3–6 months	14 (33.3)	
Above 6 months	9 (21.4)	91 (10–515)

TABLE 2 | Demographic details of Bereaved family members.

Details of family members	No of family members (%)
Gender	
Male	17 (40.4)
Female	25 (59.5)
Age	
13–17	3 (7.14)
18–30	11 (26.1)
31–45	12 (28.5)
46–60	10 (23.8)
Above 60	6 (14.2)
Relationship	
Husband	9 (21.4)
Wife	9 (21.4)
Daughter	10 (23.8)
Sister	6 (14.2)
Son	8 (19.4)
Income status	
> 10,000	7 (16.6)
10,001–25,000	9 (21.4)
< 25,000	13 (30.9)
No income	7 (16.6)
Not applicable	6 (14.2)

pelvic pain problem led to the diagnosis; unable to accept what caused the cancer, I became very depressed; the thought that I should somehow have saved him is embedded deep in my mind. I feel very guilty. I am not able to get out of my grief.

(Wife)

A few others (13 out of 42) reported that they had been accused by their immediate family and other relatives too, due to ignorance about the nature of the disease occurrence and its natural consequences. It made them emotionally disturbed, and caused sleeplessness and also led to them having suicidal thoughts. These are considered to be important obstacles to recovering from grief.

3.1.2 | A Woman Caregiver Griever Reported

My in-laws do not have such an understanding of the sudden diagnosis of cancer, and accuse me every day of not providing the right treatment for my husband's illness. I don't get any emotional comfort from them. I am therefore unable to continue my normal activities, and suffer from lack of sleep. Suicidal thoughts keep appearing. (Crying)

(Wife)

Most of them reported satisfaction, that their loved ones had been given adequate care during palliation, and the final phases. A few of them (11 out of 42) were immensely distressed while recalling the painful sufferings experienced by their loved ones at the end of their life.

3.1.3 | A Man Griever Reported

I am deeply saddened to be reminded of the physical difficulties my wife experienced in her final moments. My wife took good care of all the sufferings in the house, and what happened to her caused me a great deal of worry

(Husband)

3.2 | Expectation From the Family as Grievers

Almost half of the family members shared the problems faced during the grieving period. They said they were unable to openly shed tears, due to the relatives' ignorance and lack of understanding of their emotional needs. Family members noted that the relatives needed to have a deeper and meaningful understanding of their feelings and should facilitate the expressing of emotions in their own way.

3.2.1 | A Woman Griever Reported

"My husband was HIV positive. This embarrassment had been around for years. Again, cancer too caused a great deal of embarrassment. I used to live dependent of my husband, and I was very nervous about the future when the time came for him to die. I wanted to relax and get back to normal, I had thoughts of reuniting with the society, I had the desire to attend the bereavement meet, but the resistance from the relatives made it difficult. If I go out and look for some comfort, they forbid me under the pretext of culture and rituals". If they start permitting without reluctance, it will lead to a change in our mood.

(Wife)

3.2.2 | A Woman Griever Reported

After my husband died, the pain of grief was the worst. While trying to overcome it, the alternative view by our relatives that we should not cry, while they are giving minimal support, is distressing. I do not know exactly what to say. The message from me is that the mourner should cry. We need social support to overcome grief.

(Wife)

3.3 | Collusion Versus Emotional Conflicts

Despite the guidance of health care professionals, half of them shared that, considering the mental state of their treasured ones; the information info regarding the poor prognosis wasn't shared. Significantly, the father's short life and the lack of communication caused notable behavioural and psychological changes in the son from whom the facts were hidden. That led to a lot of distress.

What they told,

I feel so bad, I don't like my mom, and I liked my dad so much; I had spent more time with him. My mother never told me and my brother about my father's illness, I never knew he was going to die; she never told me. My mother did not give him proper treatment. That is why he died. I would have been with him, had I known. I would have talked to him. I cannot bear it. I get angry, I can't sleep at night, I cry, why did this happen, I don't like my mom.

(Son)

3.3.1 | Another Griever Spoke About Hiding Fact From Her Son

"After hearing such shocking news, in the early days, I could not stabilize my mood and hid the news that he (her husband) was going to die, from my son. At that point I avoided telling my son, thinking that I should not do so, as it would cause more pain. Because of that my son does not talk to me and has behavioural changes. He is very angry, avoiding conversations and is continuing to walk away" These are the ones that cause me the most stress

(wife)

3.3.2 | A Third Example of the Griever Shared Collusion Towards Her Husband

At that time, I was advised by the doctors to tell my husband the news about the short lifespan. I didn't take them too seriously. But now I have thoughts about them. Had I told, I would have had an idea of his needs and would have been able to help. This thought causes me a great deal of distress now-a-days.

(Wife & Daughter).

3.4 | Challenges During COVID

Most of the family members shared their experiences during the COVID pandemic restrictions. The Practical restriction that was

experienced by them was the inability to receive physical assistance from other relatives. They felt physically distressed and had a sense of incomplete funerals. Inability to meet close relatives and get emotional support was bothering them. The thoughts of dissatisfaction made them worried.

3.4.1 | One Male Griever Saying

"At a time when there were COVID related restrictions, our relatives could not come and meet us, so I felt that her death and important meetings with relatives did not take place". As I was old, I found it physically very challenging to take care of my wife alone. I could not even get help from my sons at that time.

(Husband)

3.4.2 | Some of the Griefers Said About the Inability of Others to Attend the Funerals

My husband was very influential in the place where he worked; and he suffered a lot from this cancer. The fact that the general public did not attend the funeral due to the restrictions, and that a large-scale meeting did not take place, seems to be somewhat incomplete.

(Wife)

3.4.3 | Another Had the Following Experience When Faced With Travel Restrictions, During Emergency Care

As a daughter, when my father was treated for his cancer, I was aware that it could not be cured. That the only way to live without suffering was supportive care, as advised by doctors. We had problems with travel restrictions during COVID, at that time. I had to go to the hospital and see the doctor because of my father's suffering. We had difficulty getting immediate medical attention for serious physical problems due to travel restrictions. That moment we became very nervous and anxious.

(Daughter)

3.5 | Coping With Self & With Others

The primary family members were able to provide adequate emotional support to a majority of the family members. Only a few members of the family were said to be coping with their responsibilities. Finding an employment and being financially self-sufficient helped them cope better.

3.5.1 | A Woman Griever Reported

After a long struggle, I tried to get out of my grief. Unfortunately, I could not get emotional support from others and tried to cope with my grief and my financial problems on my own. I started my journey as a cooking master in a private sector. After a few months I got busy with my routine, I am interested in my work. When I am busy with my work, I get distracted, and deal with my distress through hard work.

(Wife)

3.5.2 | Another Female Griever Reported, That Primary Family Members Were Actively Involved to Provide Emotional Support

“I think a lot about my husband after we lost him. Initially I was trying to avoid these thoughts. Now I do not ignore them his. I try to accept that he is not with us. When I think about him, I am now able to reassure and distract myself, with the support of my son and daughter. I have more time to spend with my grandchildren.” My son spends time with me after his work.

(Wife)

3.5.3 | A Third Example of the Family Member

I am a retired music teacher. I know how to engage myself in my routine. I was saddened after the death of my husband, but after that I slowly prepared myself and started my music training classes at home for the neighbourhood kids. I love music, which helps me forget my sad memories.

(Laughs) (Wife)

3.6 | Gratification With Care

The majority of them were extremely happy with how they were cared for, and how well they were treated. Nurses had assisted in providing timely home and medical treatments. Patients were also relieved to obtain prompt medical treatment from nurses on time at home.

3.6.1 | A Woman Griever Saying

We are glad that my mother-in-law was able to get her breast wound dressing and pain management at home, and at hospital. It was provided to my mother-in-law in a timely manner, which then helped me to

deal with the issues of feeling guilty.

The nurses had come home and provided adequate medical care at the required time, without grimacing, and with total empathy. We were very satisfied with them. Our mother-in-law was comfortable.

(Daughter in law)

3.6.2 | Another Grieving Woman, With the Help of Nursing Care, Was Able to Provide Care at Home

“The cause of my husband’s cancer and his subsequent death was his smoking habit. This led to cancer of the cheek. The wound was so big, that I felt frightened, and hesitant about dressing his wound every day. During that time, I learned to clean the wound with the help of nurses, and after much effort I learned and did it myself at home for my husband. And I did my duty well and felt satisfied”. I feel contented about that.

(Wife)

4 | Discussion

The study focuses on the experiences of grieving family members. Although many people shared positive coping experience, some of the Family Grievors have also reported distress [9, 14–17]. The primary cause of their distress could be attributed to unexpected death of a loved one at a young age [13, 15, 18] or incidental diagnosis of advanced disease that had led to palliation at the outset. When compared with the Family Grievors of such patients, patients who had been treated for some time were less likely to be distressed, as they were able to expect and accept the loss at some point.

The secondary cause of the caregivers’ distress is associated with impressions of guilt [19, 20] and 38 and blame received from their relatives [14, 21, 22] (the relatives would conclude that that the caregiver did not provide adequate medical treatment for the patients) [22]. This, in turn, caused a significant emotional impact in their daily lives. This only happens when their relatives were not a part of the palliative/end of life consulting sessions [21]: thereby having poor understanding of the nature of the disease and its progression [23].

The expressed grief of the family members and the misunderstandings of the other relatives play a major role in the caregiver’s grief recovery process. In dealing with grief, nearly half of the Family Grievors stated that they could not express their grief/anguish for their loved ones in their own way (as the other family members ask them to control their emotions and not to cry). Owing to this factor, they were not able to achieve emotional ventilation, which only causes further distress in them, and thus delaying their recovery from grief. The inability of other relatives to understand the nature of grief, and the lack of awareness in its recovery process, certainly influences the grief recovery of the bereaved.

Most of the people, who participated in this study, were already given the prognostic information by the health care professionals and this had been reinforced by the psycho oncologists. The importance of disclosing this to the patient and the caregiver is emphasised. (Either directly to the patients or through the care givers of the patients). This had made them feel relieved and satisfied in comparison to those who refused to report the prognosis to their loved ones (because of their own distress, perceived thoughts that disclosure might cause mental distress to the patients) [22, 24]. They tend to feel guilty later, remembering those moments when they had decided to hide the truth.

The psychological distress of the children in the family was significant [25, 26]. Keeping the fact that they were minors, the caregivers had hidden the prognostic information about the patient, and this consequently had adversely affected the emotional & behavioural patterns of the individual minors (Marcussen et al. [13]). The thought that had they known the information in advance, they might have spent the last few days closely with their loved ones, has created emotional conflicts within the family, and created maladaptive behavioural changes. This is also caused additional worries to the Family Grievers [22, 23].

Almost, all the family members said, they were able to get the medical assistance they needed during patient's ailment & pain management (especially for breast, and head & neck wound managements). In times of COVID pandemic when their loved ones had undergone sufferings related to the illness, with the help of nurses' home visit, the caregivers felt satisfied and happy [3, 15, 27] as their service fulfilled the patient's requirements [1, 18, 28, 29], amidst the general difficulties [15, 27].

However, during intense COVID pandemic lockdown, the caregivers shared the practical issues they encountered [25]. They had significant challenges compared to the usual days. During the palliation and end of life phases, patient's companions experienced compulsive physical distress [15, 27, 30] and anxiety (as only single person often accompanied the patient throughout the hospitalisation, due to practical complications like travelling restrictions, lack of accessibility [19] etc.)

Positive personal changes such as feeling of contentment and gratification for caring for their loved ones was expressed by the patient's family. People felt their life was more meaningful when they were involved in helping their loved ones during wound dressing and timely medicine administrations [29]. This even helped them to overcome their grief. The successful management of grief recovery was related to the understanding & cooperation of the other family members of the bereaved ones [28, 29]. Revealing the prognosis to the caregivers and enhancing the support system through family [14] and social circle can be a positive factor in improving the quality of life of the grieving person [22, 29, 31].

The bereavement meeting is a group intervention which aims at prevention of severe psychological impact among grieving family members. These also help to reduce the likelihood of developing complicated grief including risks of major depression or anxiety. The members are encouraged to interact and

express their emotional challenges, grieving patterns and coping strategies. The strength of this meeting is that by voicing their grieving and coping mechanisms, the Family Grievers are also able to help others and themselves by listening to the varied experiences across the group. A better understanding of the bereavement meets and breaking the taboo associated with participation might help the grievers go through the grieving process with some ease [18].

Despite all this some Family Grievers may require professional help. However, taking professional help for the same is often looked down upon. The fact remains that professional support, especially via Professional support groups, can help many grievers overcome their distress at ease [16, 32, 33].

4.1 | In Conclusion

This study highlights the psycho-social experiences of family members during illness or loss. A deeper understanding of grief and its emotional impacts will enable relatives to better support grieving family members. To fully comprehend the severity of the illness, relatives should seek appropriate information from healthcare professionals, helping to minimise conflicts between the grieving and their family members. It is also crucial to involve minors in discussions about the patient's prognosis to identify their psychological needs and stress their importance. Caregiving, especially during illness or loss, presents significant emotional and practical challenges, including issues such as family dynamics and external stressors like the COVID-19 pandemic. Nevertheless, caregivers often experience fulfilment and develop coping strategies to manage these difficulties. Addressing both emotional and practical aspects of caregiving, particularly in crises, is essential to effectively support family members through their journey.

4.2 | Study Limitations

This study was conducted in a small group, a single centre study. We have compiled the experiences of those who were interested in the bereavement support group meetings. We could have had more significant experiences if we had been able to explore the experiences of those who were unable to attend the meeting. They may have caused a change in the results of the study.

4.3 | Clinical Implication

Globally, bereaved family members are having emotional and psychosocial impact with the loss of their loved ones. The emotional challenges are mostly unspoken because of fewer support systems. In the oncology practice, facilitation of breaking bad news regarding poor prognosis without collusion, to the patient and caregivers would be effective in acceptance of possible supportive managements at the palliation and end of life phase, which will in turn help cope the intensity of grief during the bereavement phase. According to present study, during the palliative and the end of life phase, the services

provided by Hospice care and the House visit facility for the patients, has tremendously helped them in their wellbeing and caregivers felt contended and gratified. Across the globe, besides Hospice services, increasing Home care facility will benefit for the patient as well as the caregivers. We recommend that, in future, creating awareness of grief support and easy accessibility to such facility be provided by Hospice centres would enable the grievers to ease their grief, thereby improving Quality of Life.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data of this study can't be shared publicly due to presence of sensitive (confidential) participants' information.

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