

## Primary Caregiver Challenges and Experiences of Dealing with Terminally Ill Family Members

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### ABSTRACT

The role of a caregiver can be challenging and it might impact their physical and psychological well-being. There can be a variety of emotional experiences that primary caregivers might go through, along with a plethora of challenges, ranging from physical (such as burnout or exhaustion), emotional (comprising of hopelessness or despair), mental (like apprehension), financial issues, etc. The main intention of the research is to throw more light on the 'caregiving' perspective of looking after a terminally ill patient. Most of the existing work is done in the field of psycho oncology and talks extensively about cancer patients and their caregivers. Contrarily, the present study is among patients suffering across a range of ailments, and hence aims to be inclusive and varied in that aspect. Another unique factor is its novelty in Indian context. Most of the work done previously talks about Asian cultures, but not particularly about the Indian population (Kim et al., 2019) pertaining to the current point of consideration which talks about the younger generation taking up the active role of a caregiver for an elderly terminally ill family member. The caregiving process comprises of 'filial duty' of the caregiver towards to the respective ailing individual (Mok et al., 2003). The objective of the current research is to explore the challenges and experiences dealt by the primary caregiver of a terminally ill family member. This work will further facilitate researchers' insight into caregiver's perspective while caring for their loved one. An unstructured qualitative interview is conducted among primary caregivers whose family members are suffering from terminal illness. Further, thematic analysis is done to arrive at respective themes of the subsequent research findings. Sample is chosen on the basis of purposive and snowball sampling. The emerging themes that are most likely to be generated from the research are changes in current life situations, compromised self-care, caregiver duties or roles, previous experiences in similar situation, emotional experiences, caregiver burnout, resilience despite discomfort, coping strategies, interpersonal bond affecting caregiving.

**Keywords:** *Primary Caregiver, Emotional Experiences, Physical, Emotional and Mental Challenges*

Looking after a terminally ill person 24\*7 can be extremely taxing and in turn take a toll on one's physiological as well as psychological well-being for various reasons. It is directly proportional to the amount of time one is ill or needs to be taken care of.

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Received: April 14, 2023; Revision Received: December 27, 2023; Accepted: December 31, 2023

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Increase in time also elevates feelings of helplessness, hopelessness and despair not only upon patients but their caregivers as well (Sharma et al., 2020). There can be a variety of emotional experiences that one might go through during the whole period, which is what I would be pondering upon in this study. Along with these, a plethora of challenges are posed upon the caregivers, ranging from physical, emotional, mental, financial issues, etc. The main focus of the research study is on primary caregiver experiences in dealing with a terminally ill family member and will throw more light on the 'caregiving' perspective of looking after a terminally ill close one.

Another facet ought to be explored is the interpersonal relationship between caregiver and patient and how it affects the former's coping response to impending death of the patient, or how in general they react to the whole situation. Their personal bond and how close they are to each other may have an impact on how the caregiver chooses to react (Trembl et al., 2021).

The term "end-of-life care" refers to the support and medical treatment provided in the days and weeks leading up to death. This form of treatment isn't limited to the seconds before the heart stops pumping and breathing stops. Older adults frequently suffer from one or more chronic illnesses and require extensive care in the days, weeks, and even months leading up to death ("Providing Care and Comfort at the End of Life", 2022).

Depending on a person's preferences, needs, or decisions, the end of life might take on a variety of forms. Some people prefer to die at home, while others would rather be treated in a hospital or institution till the very end. The current study would focus solely on patients who are terminally ill and taken care by primary caregiver either in their homes or hospital. Physical comfort, mental and emotional needs, spiritual requirements, and practical duties are all important to those who are dying. Of course, the dying person's family additionally requires assistance with both practical responsibilities and emotional pain. There are different preference states that exist in EOL care discussions, life-sustaining preferences, uncertain states, nutrition-preferring states and comfort-preferring states (Wen et al., 2019).

For terminally-ill patient, life has a completely different meaning than the one having a healthy functioning life. Discussions with physicians and their take on whether the patient might be able to lead an acceptable and appropriate state of living (physiologically as well as mentally) is of utmost importance.

Health care is shifting from the hospital to the community and family as the population ages and the number of individuals living with chronic disease rises. (Liu et al., 2020)

Long term care for patients and loved ones relies heavily on family members. Caregiver burden, according to Pearlin and Skaff, is comparably likened to being subjected to a severe, long-term chronic stressor. The lack of understanding about caregiver load could have far-reaching consequences for the global healthcare system. The pressure or weight carried by a person caring for a chronically ill, disabled, or elderly family member is known as caregiver burden. The well-being of global healthcare system may suffer serious repercussions as a result of the lack of knowledge regarding caregiver burden. Caregivers' burden refers to the stress or weight they bear when taking care of a loved one who is chronically ill, disabled, or old. Caregiver load is associated with both the individual caregiver's and the caregiver is linked to caregiver load. The concept of burden was first proposed by patient's wellbeing. Hoenig and Hamilton, who argued that burden could be split into subjective and objective burden. Subjective burden is defined as occurrences or actions that occur as a result of

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negative caring experiences, whereas objective burden is defined as events or activities that occur as a result of negative caring experiences.

They were the first to put forth the idea of burden, arguing that there were two types of burden: subjective and objective. In contrast to objective load, which is defined as events or activities that come from unpleasant caring experiences, subjective burden is defined as occurrences or acts that result from those experiences. According to Zarit, Reever, and Bach-Peterson, "the extent to which carers perceived their emotional, physical health, social life, and financial status was as a result of caring for their relative,".

Stress among caregivers is both emotional and objective. Subjective stress refers to the caregiver's emotional or cognitive responses, such as weariness, inequality, or the current situation of caregiving. Objective stress is mostly a reflection of the caregiver's care responsibilities, and it is a measurement based on the needs of care recipients (Liu et al., 2020).

Compassion is described as the feeling of compassion for another's suffering and a desire to alleviate that person's suffering. It consists of two parts: the subjective experience of caring for someone who is suffering and the motivation to alleviate pain (Joan,2012). Undoubtedly, compassion is one of the key components when we talk about caregiving. Without the feeling of sympathy or concern for another, it is not practically possible to provide care or comfort to the one in need. But alongside, self-compassion is also one identifying feature. When one is dealing with a terminally ill patient, especially a family member, it is imperative that some amount of emotional aspect will be involved in their decision-making and reaction to the particular situation. As mentioned earlier, caregiver burnout can be easily noticed among primary caregivers as looking after someone for a considerable period of time comes with its own share of cons, sacrifices and detrimental impact on caregiver's physical as well as mental health. During such times, self-compassion and compassion might witness conflict, i.e., whether to think about one's own well-being or to take care of the ailing individual.

### ***Research Paradigm***

The philosophical assumption for the particular study is interpretivism. Interpretive researchers think that reality is made up of people's subjective perceptions of the outside world; as a result, they may subscribe to an inter-subjective epistemology and the ontological idea that reality is socially produced. Interpretivists, according to Willis (1995), are anti-foundationalists who believe there is no single proper path or approach to knowledge. Walsham (1993) claims that there are no 'right' or 'incorrect' hypotheses in the interpretive tradition. Instead, they should be rated on how 'interesting' they are to the researcher and others working in similar fields. They try to draw their constructs from the field by studying the phenomenon of interest in depth.

### ***Objectives of study***

- To determine the interpersonal relationship between primary caregiver and patient.
- To explore the challenges and experiences involved in dealing with a terminally ill family member.
- To explore the cognitive and emotional responses of the caregiver due to impending death of the patient.
- To analyze conflict (if any) in compassion and self-compassion of primary caregiver.

## REVIEW OF LITERATURE

Early start of end-of-life (EOL) care in terminally ill patients might limit unnecessary pharmaceutical administration, laboratory and radiological examinations, and treatments that can cause unintended consequences without providing significant benefits. The goal of a retrospective observational study conducted by Choudhuri and colleagues (2020) was to assess early vs. late beginning of EOL care in terminally ill ICU patients when treatment futility was recognized. It has been stated in the literature that the successful assessment of patients' clinical condition, adroit professionalism, and proper communication are more important than legal impediments or ethical compulsions in the timely implementation of EOL treatment in the ICU. Although it is true that state laws can influence the practise of EOL in terminally ill patients, the fact remains that such laws are unlikely to prevent EOL from being practised if adequate knowledge sharing is practised between the primary physician and intensivist to reach a consensus decision and a meticulously drafted communication policy is adopted to secure consent from the patients' family members. Thus, it was concluded that delaying the commencement of EOL care in terminally ill ICU patients after identification of treatment futility can increase antibiotic use and medicinal and/or surgical treatments while having no effect on family member satisfaction.

End-of-life (EOL) care that is of high quality requires a thorough assessment of terminally ill patients' preferences for EOL care and customising of care to their specific requirements. A study conducted by Wen and colleagues (2018) investigated factors that predispose cancer patients (N = 303) to specific LST (life sustaining treatment)-preference states (life-sustaining preferring, comfort preferring, uncertain and nutrition preferring).

Participants in the comfort-preferring state were less likely to prefer life-sustaining, uncertain, and nutrition-preferring states than those in the life-sustaining, uncertain, and nutrition-preferring states. Participants were less likely to be in the uncertain than in the comfort-preferring condition if they had a higher quality of life (QOL) and more depressive symptoms. Those in the state of moderate symptom distress with severe functional impairment were substantially more likely to belong to the nutrition-preferring state than those in the state of mild symptom distress with excellent functioning. It was concluded that to promote realistic expectations of LST efficacy at EOL, physicians should nurture patients' correct prognostic awareness and facilitate EOL-care talks. Clinicians should improve patients' quality of life to eliminate uncertainty in EOL-care decision-making and give enough psychological support to those who prefer comfort care exclusively.

Pre-loss grieving and, more recently, death readiness have been used to describe the time between getting a terminal ailment diagnosis and the death of a loved one. Initially, it was considered that grieving before a loss had a good effect on the bereavement outcome, but other research have produced opposite results. A study conducted by Treml and colleagues (2019) looks into the definitions and measuring instruments of pre-loss sorrow and death readiness, as well as the relationships between the two conceptions and caregiver characteristics, pre-loss psychological aspects, and post-loss adjustment in caregivers of people with terminal illness.

Poor post-loss adjustment was linked to high levels of pre-loss grieving and low levels of perceived preparedness for death (e.g., prolonged grief, depressive symptoms, etc.).

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Caregivers with a high level of pre-loss sadness and a poor level of preparedness for their loved one's death would benefit from specialised post-loss support. The operationalization of both constructs is inconsistent, which limits the results.

In a study conducted by Rocio et al., 2017, the researchers effectively came up with 7 themes pertaining to 'the essence of the hospital-home transition in patient-caregiver dyad in palliative care'. The themes they discuss are life changes, caring actions, emotional and physical burden, physical discomfort and pain, coping, bond between patient in palliative care and their caregiver dyad, and expected responses. The aforementioned findings can help in corroborating the present study findings.

Thus, above mentioned literature talks about the different studies on end-of-life (EOL) care for terminally ill patients, and consequent grief reaction of family members. These can help in establishing the base for research study.

### **METHODOLOGY**

#### ***Sampling strategy***

Purposive and snowball sampling is utilised for this particular research study. Depending on the inclusion-exclusion criteria, the sample is chosen so that they serve the purpose of study. These participants can further contact and introduce other people who will abide by the requirement criteria. Thus, this will help the researcher get hold of an impressive sample to conduct the study hassle-free.

**Sample size-** 7 participants

#### ***Inclusion criteria-***

- a) Having terminally ill family member
- b) Primary caregiving in a home setting

#### ***Process***

Conduct face-to-face interview sessions with 7 participants. The location of the interview depends on mutual convenience of the participant and researcher. Researcher might have to travel to participant's place for conduction of the interview or decide on a time and place which is suitable for both. Before conducting the interview, an informed consent form is distributed to the participants and debriefed about the whole process. After completion of interview, analysis is done by coding and generating themes for the theoretical framework.

#### ***Method of data collection***

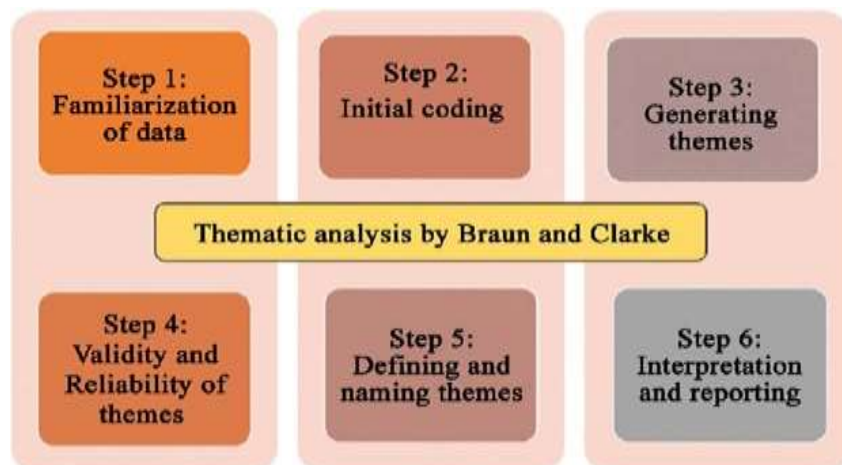
Conduct an unstructured interview for the purpose of collecting data. This will help gain better understanding and information about the particular topic, since there is limited existing knowledge about the current topic. Indirectly, it would also help the participants vent out and express whatever they feel like without any limits or boundaries, which they might have not been able to express till date.

#### ***Method of data analysis***

Thematic analysis is the method that will be used in order to analyze the current data set. It involves the technique for finding, examining, and interpreting patterns of meaning (also known as "themes") in qualitative data. The deductive approach will aid highlighting themes of interest by using an existing theory, framework, or other researcher-driven focus (Braun and Clarke 2012; Varpio et al. 2019). The external research-driven focus for current study is

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based on the study findings conducted by Rocio et al.,2017, titled “Experiences of patient-family caregiver dyads in palliative care during hospital-to-home transition process”.



*(Thematic Analysis by Braun and Clarke. Source: Braun and Clarke (2006) [10].)*

**Figure 1**

### Thematic analysis

#### *Ethical consideration*

Although the sample of study is a vulnerable population and undoubtedly it is going to be challenging, it isn't practically impossible to go about the research study. An appropriate sample size has been taken for that purpose and people who fit the inclusion criteria are accessible by the researcher. An unstructured interview will be undertaken so that the participants don't feel bound to respond to a particular set of questions. It will be a free-flow based interview where the main focus would be to gain an understanding about the research topic from the interview and what the individuals choose to disclose. There won't be any compulsion on the participants to answer what they don't feel like communicating and proper care would be taken for informed consent and comfort of the client. If they feel any sort of discomfort during the interview process, immediate termination would prevail. Post interview if they require any sort of professional assistance or help with regard to the emotional damage the interview might lead to, they will be provided with details of few counselling referrals. Thus, the research study would be conducted while abiding by the APA code of ethics and it would also seek approval of the Institutional Review Board (IRB).

## RESULTS

Upon analyzing the data, nine global themes have emerged that elicit the plethora of challenges and experiences that primary caregivers are likely to face while taking care of their family member: 1) changes in current life situations 2) compromised self-care 3) caregiver duties 4) previous experiences in similar situation 5) emotional experiences 6) caregiver burnout 7) resilience despite discomfort 8) coping strategies 9) interpersonal bond

#### **a) Theme: 1- Changes in current life situations**

Sudden shift in daily routine inevitably takes a considerable amount of time to get accustomed to. Thus, acclimatising oneself to the present situation is one task that most participants mentioned facing significant distress with.

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### **b) Theme: 2- Compromised self-care**

Consistent care for a dear one can be a cause of exhaustion for primary caregivers which consequently might lead to diminished self-care or self-compassion of the caregiver. Though most participants mentioned that particular component being their least priority, there is a significant need to maintain optimal balance while taking care of one's respective loved one and their own self.

### **c) Theme: 3- Caregiver duties or roles**

Most of the individuals hailing from an Indian (collectivist) culture tend to believe in leading their lives by being involved and invested with their respective community and try to fulfil most of their duties or responsibilities on the basis of societal norms. Thus, there exists a sense of 'duty' or 'responsibility' especially towards family members.

### **d) Theme:4- Previous experiences in similar situations**

Upon interviewing respective participants, it was observed that those who had an experience of providing primary care to any family member previously in their life, comparatively felt the journey to be "easier" for them in some way rather than those individuals who were completely new to this sort of an experience.

### **e) Theme:5- Emotional experiences**

A wide range of emotions is likely to accompany caregivers throughout the process. It might be regarding the guilt that caregivers often come across with respect to how much they are able to look after the ill person, whether they are doing enough lest something happens to the person because of their inefficiency. Another common concern area involves caregiver's concern regarding their own family and much they are able to contribute there, whether their absence will affect the members in a negative way.

Apart from this, fear of losing loved one, constant worry, apprehension, frustration, sadness, desperation to make things work out in their favour, and so on are some noteworthy experiences.

### **f) Theme: 6- Caregiver burnout**

Basic exhaustion (physiological or psychological) leading to a sense of 'burnout' among primary caregivers because of consistent caregiving to their family member is a common phenomenon that most individuals come across, and the present study findings also confer to that particular concept.

### **g) Theme: 7- Resilience despite discomfort**

Another common aspect that most participants mentioned about was to keep putting their best foot forward and continue the process of caregiving despite the subsequent challenges and emotional turmoil they were going through. Most spoke about it being their respective "duties" to look after their family members in their best capacity.

### **h) Theme: 8- Coping strategies**

Most individuals mentioned their impressive strategies as a means of coping with the distress caused because of the sudden change in their lives and the subsequent "roles" and "responsibilities" while paying the active role of a primary caregiver.

### i) Theme: 9- Interpersonal bond

Most individuals spoke about the bond they share with the respective family member they were caring for. Some mentioned sharing a close-knit relationship with them and how their subsequent reaction has been. Others mentioned about not being so close to the respective member initially, but how through the process of caregiving the mutual love and respect took an upside turn. That, no matter how close the person is to the respective family member, they have the inherent urge of looking after them in the best possible way.

## DISCUSSION

### *Changes in current life situations*

Caregivers elaborate the respective changes that has taken place in their lives since the time they have taken up the active role of a caregiver. They mentioned how it is not just their life they can solely focus on, but the patient's as well. For example, from grocery run to household chores, taking care of their own family ( for individuals who are married) as well as patient's, they talk about how their "daily schedule" and "lifestyle" has changed and so on. It is not something they complain about necessarily, but they speak about the sudden changes and its subsequent effect on their lives. Financial changes since the advent of the treatment procedure is a major area that most interviewees spoke about. How individuals have had to manage their expenses, tackle financial crunch, and be able to do it all irrespective of the toll it took on their well-being.

### *Compromised-self care*

One common aspect that was observed in almost every interview was how less time the caregivers devoted to take care of their own selves. They mentioned how prioritizing themselves or their needs was something they couldn't fancy to bother about. Especially working individuals spoke about how time management was a concern and taking out time for themselves seemed as a herculean task amidst such situations.

### *Caregiver duties*

These include all the specific roles and responsibilities caregivers mentioned keeping in mind while taking care of their family member. When we talk about the Indian culture specifically, there are certain norms and regulations one is expected to abide by, and one prominent feature of it is the sense of 'collectiveness' or 'belongingness'. In virtue of this, the younger generation is expected to extend a helping hand to the elderly, more specifically look after their parents or elders in the family. Automatically, there comes a sense of "duty" or "responsibility", a milestone that ought to be achieved. These could range between hospital or medical expenses, house rent, grocery runs, etc.

### *Previous experiences in similar situations*

Individuals who have previously experienced the caregiver role seemed to have a somewhat different approach to the prevailing situation than the ones who were being a part of it for the first time. Comparatively it seemed the former individuals to be more fluent in the path of acceptance, planning for future course of action, and more methodical as to how everything needs to be planned out, than the latter. Interviews of the latter were more rich in emotional and affective content, their sense of hopelessness and helplessness was more prominent.

### *Emotional experiences*

There exists an extensive range of emotions that caregivers mentioned about in the interviews. Certain commonalities observed among most of the interviewees include feeling



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of hopelessness, helplessness, guilt, apprehension. Majority of participants discovered that their worldviews have changed as a result of their caregiving experience, and they now value their lives better. (Mok et al., 2003)

Participants, especially females who are mothers, mentioned about a specific dilemma they often come across, which is whether or not they are doing enough for either the ailing person or taking care of their own family members (husband, children).

### ***Caregiver burnout***

It is a very natural response to feel burdened (physically, emotionally, mentally) to look after someone in general, specifically your family member in this context. Its unprecedented nature can cause serious turmoil in one's life and in various facets such as, financial, emotional, physical, etc. Thus, the subsequent reaction to constant exposure of such stressors is the feeling of 'burnout'. Reinhard & Horwitz (1995) make the distinction between objective burden (the influence on the caregiver's well-being) and subjective burden (the number of hours of caregiving, disturbance of personal routine, etc.).

### ***Resilience despite discomfort***

One striking feature among all the primary caregivers was their will to keep working towards betterment of the patient's health. Despite stating hurdles and difficulties, they hardly deterred from their action plan, which is to keep providing care to the best of their capability. Although this driving force can be steered due to the societal norms and responsibilities pertaining to looking after the sickly, there can be several other factors influencing it. Positive health outcomes of the sick person acted as a boost or reinforcer to safeguard the resilience, but even in cases where there were no positive results as such, caregivers persisted upon helping. One interviewee mentioned their father acting as 'a roof on top of their head' and that they are ready to keep him close in whichever way or form.

### ***Coping strategies***

Individuals spoke of healthy coping strategies to help them balance out the stress and daily living. Although, taking time out for oneself seemed as an impossible task, caregivers mentioned how important it is to help in the process of caregiving as well. Some of these included devoting time to things they enjoy, like gardening, listening to music, sitting in the balcony with a cup of tea, watching movies, and other minimal activities that are not so extravagant.

One of them mentioned how it is not about some sort of grand gesture for them, but simply looking outside the window of the bus, while returning from work. They described how that 30 minutes ride back home is all the time they spend for their own self. Having said these, there were no signs of regret present in that individual of not being able to do all the things they love, like travelling, partying, etc. It wasn't their priority at that moment and not something they were bothered about. What mattered the most is patient's well-being and their needs and requirements.

### ***Interpersonal bond***

Another facet that came up at a high frequency was the relationship or bond shared between the patient and caregiver. One natural assumption would be to think that strong interpersonal bonds facilitate caregiving and also caregiver's interest or motivation to keep going, amidst the emotional, financial and health burden upon caregivers. (Loboprabhu et al., 2006)

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But the analysis of certain interviews revealed that it isn't the sole way to look at the current aspect. It was observed that although the patient-caregiver dyad wasn't as successful in the beginning for certain individuals, that didn't harm the caregiving process in any way. Rather, individuals said that they grew closer to each other subsequently, and their relationship improved.

### *Implications to practice*

The practical implication of the research study is this will give an insight to the caregiving perspective and act as a medium to assist help or understanding to primary caregivers who look after terminally ill family member. Apart from this, it will also provide an understanding of the interpersonal relationship between caregiver and patient and how the bond has an effect on former's cognitions, emotions and coping responses. Along with this, the study also aims to analyze conflict between compassion and self-compassion of the caregiver, if any.

The theoretical implication is that this study is novel and not previously done in Indian context. Thus, it will act as a unique addition to existing literature, which mainly focuses on cancer population and not a more generic understanding.

## CONCLUSION

There is no set rulebook for feeling or behaving a particular way in situations where any sort of harm to loved ones are concerned. Grief is an extremely personal space, and individuals are allowed to react in ways that comes naturally to them. Having discussed the relative challenges and emotional experiences one might go through, it is not generalizable since humans are unique beings, and there is no certainty as to how one is going to perceive or react to a given situation.

Extensive review work corroborates the respective findings of the present research. The present research has been conducted in a way that it promotes inclusivity with respect to the population under study, i.e., participants ranged between ages 21 to 55. The subsequent change of their outlook is clearly identifiable, although the ulterior motive remains same for all, to provide support and care to the ailing member of the family despite all hurdles.

To talk about limitation of the work, since the inclusion-exclusion criteria is not particularly rigid, it doesn't promote specific attention to a set population, and thus the results can't extensively talk about individuals belonging to a particular age range, gender, socioeconomic class. The current research's aim is to promote more generalizability than specificity, pertaining to the current topic of discussion.

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### **Acknowledgment**

The author(s) appreciates all those who participated in the study and helped to facilitate the research process.

### **Conflict of Interest**

The author(s) declared no conflict of interest.

**How to cite this article:** Majumdar, S. (2023). Primary Caregiver Challenges and Experiences of Dealing with Terminally Ill Family Members. *International Journal of Indian Psychology*, 11(4), 3024-3034. DIP:18.01.285.20231104, DOI:10.25215/1104.285