

Grief experiences among family caregivers after providing palliative end-of-life care

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Applied Psychology Research is published by Academic Publishing Pte. Ltd. This article is licensed under the Creative Commons Attribution License (CC BY 4.0). https://creativecommons.org/licenses/by/ 4.0/ **ABSTRACT:** This study explores the diverse experiences of family caregivers providing palliative end-of-life care, focusing on their coping strategies during caregiving and their grief responses post-caregiving. Analyzing demographic profiles, the study reveals that caregivers are predominantly women, spanning various ages, socio-economic backgrounds, and familial relationships. Caregiving durations and financial conditions also vary widely, highlighting the need for tailored support services. The thematic analysis identifies two major coping strategies: avoidance (including "Freeze" and "Flight") and approach (including "Plan" and "Act"). Participants predominantly employed "Act" strategies, reflecting proactive engagement with caregiving challenges. Post-caregiving grief responses were categorized into four sub-themes: prolonged grief, anticipatory grief, irregular grief, and normal grief. The study underscores the necessity of personalized support programs that address both coping strategies during caregiving and diverse grief responses afterward. Recommendations include developing flexible support services that provide financial assistance, emotional support, and practical resources, as well as grief support tailored to different grief experiences. By aligning interventions with the varied needs of caregivers, practitioners can enhance support and improve caregivers' overall well-being.

KEYWORDS: grief experiences; family caregivers; palliative care; end-of-life care; applied psychology; content analysis

1. Introduction

Grief experiences, characterized by emotional, psychological, and sometimes physical responses to loss, are complex and multifaceted processes^[1]. These experiences can manifest in various ways, including feelings of sadness, longing, anger, guilt, and confusion. Grief is not a linear process but rather a series of fluctuations and adjustments over time as individuals come to terms with their loss and adapt to life without the deceased. When family caregivers provide palliative end-of-life care to their loved ones, the grief they experience takes on a distinctive quality shaped by various factors^[2]. Firstly, caregivers often form deep emotional bonds with those they care for, particularly in the context of end-of-life care, leading to an intense emotional investment in the relationship. This emotional attachment heightens the impact of grief when the loved one eventually passes away^[3]. Secondly, the caregiving role itself can be immensely demanding, encompassing physical, emotional, and psychological challenges, especially when witnessing the suffering of their loved ones in palliative care settings^[4]. This burden and strain

associated with caregiving contribute significantly to the complexity of grief experiences. Moreover, family caregivers may experience anticipatory grief as they anticipate the forthcoming loss of their loved one^[2]. This anticipatory grief may intensify as the end-of-life period draws near, compounding the emotional toll on caregivers. Additionally, caregivers in palliative care may grapple with ambiguous loss, where the physical presence of the loved one remains, but they begin to mourn the loss of the person they once knew due to changes in health and functionality^[4]. This ambiguity can exacerbate the grieving process, adding layers of complexity to their experiences.

Throughout their caregiving journey, caregivers may navigate a myriad of emotions, ranging from relief that their loved one's suffering has ended to guilt for feeling relieved and profound sadness over the loss^[2,4]. These mixed emotions reflect the intricate nature of grief in palliative care contexts. Even after the death of their loved one, family caregivers may continue to grapple with grief as they adjust to life without their presence^[1]. This enduring impact underscores the profound and lasting effects of caregiving experiences on grief. Therefore, it is necessary to investigate and understand the grief experiences of family caregivers^[5]. in palliative care settings so that they may be provided targeted support and interventions to help them navigate their grief journey effectively^[2,4] through the objective of exploring the experiences of family caregivers^[6] during their caregiving experiences^[7], and drawing insights to inform targeted interventions aimed at supporting caregivers in the palliative care setting^[8]. As a rationale for conducting this study in applied psychology, research underscores the significant emotional burden and complex grief experiences that family caregivers endure after providing palliative end-of-life care. It was revealed that discrepancies between terminally ill elders and their caregivers, such as elders' reluctance to accept dependence and fears of being a burden, can heighten emotional distress for caregivers^[9]. Similarly, the intense demands of caregiving often lead to prolonged grief, complicating the transition from caregiving to grieving^[10]. These findings point to a critical need for applied psychological research to develop interventions that specifically target both anticipatory and prolonged grief among family caregivers. Addressing these challenges can improve caregivers' mental health and well-being during and after the caregiving process.

1.1. Research questions

(1) What is the demographic profile of family caregivers who provided palliative end-of-life care?

- Sex
- Age
- Family income
- Relationship to the family
- Duration of caregiving
- Type of illness
- (2) What are the experiences of family caregivers during and after providing palliative end-of-life care?
- (3) What insights can be drawn from the experiences of family caregivers providing palliative end-oflife care, and how can these insights inform targeted interventions?

1.2. Theoretical framework

The Family Systems Theory, developed by Murray Bowen^[11] in the 1950s and 1960s, offers a conceptual framework for understanding the emotional dynamics within families. Key components of this theory include Differentiation of Self, which explores an individual's ability to maintain a sense of self within the family, Triangles representing stable relationship units, and the Family Projection Process, which examines the transfer of emotional issues across generations^[12]. In line with this theoretical

framework, our research on the experiences of family caregivers in palliative care aims to investigate how differentiation of self affects caregiving dynamics, utilize triangles to understand emotional interactions during different caregiving phases, and examine the family projection process to shed light on the transfer of emotional issues that affect the specific needs expressed by family caregivers^[13]. By applying these theoretical concepts, we aim to unravel the emotional connections among family members and understand how these dynamics shape the caregiving experiences and needs throughout the palliative care journey.

2. Method

2.1. Research design

The qualitative research design employed in this study is a case study approach. This approach allows for an in-depth exploration of specific instances or cases of caregiving in the palliative care setting. By focusing on individual cases, the researchers investigated the unique circumstances, contextual factors, and challenges faced by family caregivers providing end-of-life care. This approach enabled a comprehensive examination of both the subjective experiences of caregivers and the broader contextual and systemic issues influencing caregiving experiences in the palliative care context.

2.2. Participants of the study

For our study, we purposefully invited a group of 13 participants who had firsthand experience in providing palliative end-of-life care to their family members. We used purposive sampling to select individuals with specific characteristics or experiences that were relevant to our research. Additionally, we used the snowball sampling method to expand our participant pool. This involved the initial participants helping us recruit others who met our study's criteria. By using this combined sampling approach, we were able to ensure that our participant group would offer a wide range of insights into the complex world of palliative end-of-life care within families.

2.3. Research instrument

In this study, the research instrument primarily involved semi-structured interviews as the primary method of data collection. An aide-memoire (Table 1) was designed as the interview protocol to facilitate an in-depth exploration of the experiences of family members in the context of palliative end-of-life care. The questions were crafted to elicit detailed narratives, capturing the emotional, social, and practical dimensions of their caregiving journeys.

Table 1. Aide-memoire.								
Questions asked								
Experiences of family caregivers during and after providing palliative end-of-life care	"What were some of the most significant challenges you faced as a family caregiver during the palliative end-of-life care of your loved one?"							
Insights be drawn from the experiences of family caregivers providing palliative end- of-life care as basis for informing targeted interventions	"What key insights or lessons have you gained from your experience as a family caregiver providing palliative end-of-life care? Moreover, how do you believe these insights can be utilized to develop targeted interventions or support programs to better meet the needs of family caregivers in similar situations?"							

2.4. Data gathering procedure

The data gathering procedure involved conducting face-to-face interviews with 13 family members who had firsthand experience providing palliative care. Each interview took place in a relaxed setting,

where the researcher and the participant engaged in a personal conversation. The atmosphere was designed to ensure that participants felt comfortable sharing their experiences openly. Interview questions were thoughtfully crafted to cover various aspects, including the emotional, social, and practical dimensions of the caregivers' journeys. Throughout the interviews, the researcher actively listened and encouraged participants to share their stories. Probing questions were used to delve deeper into specific aspects, allowing for a comprehensive understanding of the nuances within their experiences. The face-to-face interaction provided a platform for participants to express themselves freely, ensuring that the data collected was detailed and reflective of their unique perspectives and challenges. The process was iterative, with the researcher adapting the conversation based on the participant's responses, allowing for a dynamic exploration of the topics. Emphasis was placed on creating a supportive and open environment throughout the data gathering procedure, facilitating the sharing of personal and sometimes sensitive experiences related to providing palliative care.

2.5. Data analysis

The researchers utilized content analysis and thematic analysis for data analysis. We conducted content analysis by systematically categorizing and quantifying the responses from participants, identifying recurring keywords and concepts to highlight common challenges and insights by counting the frequency of these codes to underscore the most significant patterns. Additionally, we performed thematic analysis to interpret underlying themes and patterns within the data, exploring major themes and subthemes to understand the broader experiences of family caregivers and to inform the development of targeted interventions and support programs.

3. Results

3.1. Demographic profile of the participants

The description of the participants (Table 2) revealed that most caregivers are women, which highlights the important role that women play in supporting their family members who are ill. The age range of the participants is from 21 to 66 years old, showing that caregiving is not limited to a specific age group. It is something that people do at different stages of their lives. The family incomes of the participants vary widely, ranging from 5000 to 90,000 per month. This shows that caregiving cuts across different socio-economic backgrounds. Caregivers come from different financial situations and take on the responsibilities of providing care. The wide range of family incomes also suggests that these caregivers may have different resources available to them. This could affect their ability to access support services and manage the financial aspects of caregiving. The caregivers in the dataset are caring for a variety of family members, including mothers, fathers, grandparents, uncles, and brothers. This shows that caregiving involves a complex network of familial relationships. Caregivers are stepping into the role of primary support for their family members. The duration of the caregiving experiences ranges from one month to eight years. This shows that caregivers are committed and resilient. For example, caring for a family member with Alzheimer's for eight years or providing support for a grandmother with breast cancer and Alzheimer's for three years requires dedication and endurance. The health conditions of the family members who are being cared for also vary. Some have heart failure or liver cirrhosis, while others have more complex cases like cancer or Alzheimer's. This diversity in health challenges highlights the need for caregivers to adapt to different medical needs and provide comprehensive support to their family members.

Applied Psychology Research 2023; 2(1): 1307.

Code	Sex	Age	Family member cared of	Months/Years cared for	Family income	Type of illness
S1	F	53	Mother	2 months	13,000	Heart disease
S2	F	41	Father	2 months	5000	Heart disease
S3	F	47	Mother	1 year	30,000	Liver sclerosis
S4	F	66	Mother	1 month	60,000	Pancreatic cancer
S5	F	22	Grandfather	1 month	10,000	Heart failure and pulmonary edema
S6	М	22	Grandmother	3 years	20,000	Breast cancer and Alzheimer
S7	F	65	Mother	8 years	35,000	Heart disease and failure, pneumonia and Alzheimer
S8	F	21	Uncle	3 months	90,000	Lung cancer
S9	F	42	Father	1 month	5000	Bone cancer
S10	F	21	Grandmother	5 years	60,000	Pancreatic cancer
S11	F	54	Mother	3 years	10,000	Parkinson's disease and heart complication
S12	F	64	Brother	1 year	10,000	Lung cancer
S13	F	47	Father-in-law	8 years	10,000	Emphysema and Alzheimer

Table 2. Demographic profile of the participants.

3.2. Experiences of family caregivers during and after providing palliative end-of-life care

In this study, our emergent findings revealed coping strategies employed by family members providing end-of-life palliative care, focusing specifically on the major theme of avoidance and approach. Within the framework of this theme, we identified two primary sub-themes: avoidance, which encompasses strategies aimed at evading or minimizing exposure to stressors, and approach, which involves strategies aimed at directly confronting or managing stressors. Under the Avoidance sub-theme, we further delineated two distinct strategies: freeze, characterized by a state of immobility or paralysis, and flight, involving efforts to escape or avoid stressful situations. Conversely, within the Approach sub-theme, we identified two complementary strategies: plan, which entails the development of proactive approaches and action steps, and act, which involves the direct execution of strategies to address or mitigate stressors. Through an exploration of these sub-themes and their interplay, we aim to gain a nuanced understanding of individuals' coping mechanisms in response to stress and threat. Additionally, relevant references are provided to support and contextualize our findings within existing literature on coping strategies and psychological resilience.

In this qualitative study, the major theme (**Table 3**) centered on the interplay between avoidance and approach behaviors, with distinct sub-themes emerging under each category. Within avoidance, the selected participants recounted experiences characterized by "Freeze," where hesitation prevailed, and "Flight," reflecting a tendency to distance themselves from responsibilities. Conversely, the theme of approach unfolded through the sub-themes of "Plan," involving deliberate strategizing and preparation, and "Act," where the selected participants described proactive and immediate engagement with challenges. These insights, obtained from the narratives of selected participants, offered an understanding of how individuals navigated the complex dynamics of avoidance and approach in response to various life challenges, contributing valuable perspectives to the broader understanding of human behavior.

Major themes	Sub themes
Avoid	Freeze
	Flight
Approach	Plan
	Act

Table 3. Emerging major themes from experiences of family caregivers during providing palliative end-of-life care.

The data presented in **Table 4** depicts the responses of participants regarding their utilization of avoidance and approach strategies in coping with stressful or threatening situations. Within the major theme of coping strategies, participants revealed engagement in both avoidance and approach behaviors. Under the avoidance category, participants acknowledged employing two distinct strategies: freeze and flight. Freeze, characterized by a state of immobilization or paralysis in response to stress, was reported by nine participants. Flight, involving efforts to evade or distance oneself from stressful situations, was acknowledged by four participants. Conversely, within the approach category, participants reported two primary strategies: planning and acting. Planning, involving proactive formulation of action plans, was indicated by six participants. Acting, which entails direct confrontation or management of stressors through action-oriented strategies, was the predominant approach, with thirteen participants endorsing this strategy. These findings underscore the varied coping mechanisms individuals employ when faced with stress, highlighting the prevalence of both avoidance and approach strategies within the participant group.

Table 4. Content analysis presentation of family	caregivers' experiences	s during providing end-of-	life care in the palliative stage.

Avoid	S 1	S2	S 3	S4	S 5	S6	S 7	S 8	S 9	S10	S 11	S12	S 13	Total
Freeze	/			/	/	/	/	/	/		/		/	9
Flight	/			/						/		/		4
Approach														
Plan		/	/		/	/		/		/				6
Act	/	/	/	/	/	/	/	/	/	/	/	/	/	13

For Avoidance, the participants' narratives in the study provide valuable insights into the coping mechanisms employed when faced with the challenges of palliative end-of-life care. The analysis revealed distinct patterns of responses, with some individuals exhibiting a freeze response while others leaned towards flight behavior. The freeze response, characterized by fear, shock, and emotional immobilization, was evident in the narratives of nine participants who described feelings of being caught off guard, overwhelmed, and deeply saddened by the sudden and distressing events surrounding their loved ones' illnesses. These participants expressed a sense of emotional paralysis and dissociation as they grappled with the emotional impact of the impending loss. In contrast, four participants exhibited flight behavior, as they sought to avoid conflicts, withdraw from social interactions, and emotionally distance themselves from the stressors associated with their loved ones' illnesses. Their narratives reflected a reluctance to confront the harsh realities of their situations, instead opting to maintain emotional and physical distance and hold onto hope as a coping strategy.

On the other hand, the analysis of the participants' narratives on the major theme approach revealed distinct patterns of behavior consistent with the concepts of plan and act within the approach theory. The plan approach, characterized by a commitment to a predetermined course of action aimed at achieving

specific results, is evident in the deliberate and thoughtful responses of selected participants. Selections 2, 3, 5, 6, 8, and 10 exemplify proactive planning and decision-making in response to the challenges of caregiving. Participants in these selections consciously assume caregiving responsibilities, make strategic decisions to address evolving health conditions, and coordinate efforts within their families to ensure the well-being of their loved ones. The narratives highlight the participants' structured and intentional approach to caregiving, emphasizing the importance of planning as a means of navigating complex caregiving dynamics and addressing the diverse needs of their family members. Conversely, the concept of act within the approach theory signifies the participants' active engagement and hands-on approach to caregiving responsibilities. All thirteen selected participants demonstrate behaviors consistent with the act in approach theory, indicating a proactive and goal-oriented orientation in their responses to caregiving challenges. Through their narratives, participants describe taking initiative, actively facing challenges, and executing planned or spontaneous actions to achieve desired outcomes. Their accounts illustrate a hands-on approach to caregiving tasks, including personal care, household chores, and emotional support, underscoring their commitment to actively caring for their loved ones and addressing their evolving needs.

In the qualitative exploration of grief experiences as seen on **Table 5** among family caregivers after providing end-of-life care, the major theme focused on understanding how individuals cope with the profound emotions associated with loss. Through participants' narratives, four distinct sub-themes emerged: "Prolonged Grief," "Anticipatory Grief," "Irregular Grief," and "Normal Grief", as outlined by Karen Roldan's "Types of Grief: The 16 Ways People Grieve." Within the "Prolonged Grief" subtheme, two participants shared experiences characterized by enduring and persistent mourning that extended beyond conventional timelines. Additionally, two participants contributed to the "Anticipatory Grief" sub-theme, shedding light on the emotional challenges associated with anticipating an impending loss. The "Irregular Grief" sub-theme arose from the narratives of four participants, showcasing unique and non-traditional expressions of grief that diverged from conventional norms. Most notably, five participants fell under the "Normal Grief" sub-theme, representing a more expected and conventional response to loss. Together, these sub-themes, involving a total of thirteen participants, provided a nuanced understanding of the diverse ways individuals navigate the grieving process. This exploration offers valuable insights into the complex nature of grief experiences, offering guidance for practitioners in psychology and counseling to tailor support and interventions to meet the varied needs of those undergoing the grieving process.

Major theme	Sub themes
Grief	Prolonged
	Anticipatory
	Irregular
	Normal

Table 5. Emerging major themes from experiences of family caregivers after providing palliative end-of-life care.

The qualitative exploration (**Table 6**) of grief experiences among study participants reveals four distinct sub-themes: prolonged grief, anticipatatory grief, irregular grief, and normal grief. Prolonged grief, demonstrated by participants S1 and S4, denotes an enduring mourning process surpassing conventional timelines, necessitating sustained and specialized support. Anticipatory Grief, exemplified by S2 and S3, showcases proactive emotional preparation for impending loss, emphasizing the need for tailored interventions to assist individuals in navigating pre-loss grieving complexities. Irregular grief,

depicted by participants S5, S6, S8, and S10, manifests as intense and extreme reactions to loss, highlighting unique coping mechanisms and emotional turbulence beyond traditional mourning patterns. Normal grief, observed in participants S7, S9, S11, S12, and S13, signifies a conventional emotional response to loss, reflecting a range of expected and adaptive grieving behaviors. The study findings underscore the importance of personalized and empathetic support strategies tailored to the diverse challenges associated with each sub-theme of grief.

 Table 6. Content analysis presentation of family caregivers' experiences after providing end-of-life care in the palliative stage.

	P 1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12	P13	Total
Prolonged grief	/			/										2
Anticipatory grief		/	/											2
Irregular grief					/	/		/		/				4
Normal grief							/		/		/	/	/	5

3.3. Insights drawn from the experiences of family caregivers providing palliative end-oflife care

The diversity in the demographics and caregiving experiences of the participants highlights the need for tailored support services that address the varying needs and circumstances of caregivers. Given that most caregivers are women and the caregiving experience spans different ages, socio-economic backgrounds, and familial relationships, it is essential to develop targeted interventions that reflect this diversity. It is recommended to design and implement support programs that are flexible and inclusive, considering the varied financial situations, caregiving durations, and health conditions of family members. Support services should offer financial assistance, emotional support, and practical resources tailored to the specific challenges faced by caregivers. Programs could include educational workshops on managing different health conditions, peer support groups for sharing experiences, and financial planning assistance to help caregivers navigate the economic impact of caregiving. By addressing these diverse needs, interventions can better support caregivers in their crucial roles and improve their overall wellbeing.

The thematic and content analysis of family caregivers' experiences during and after providing palliative end-of-life care reveals a complex array of coping strategies and grief responses. The findings indicate that caregivers employ both avoidance and approach strategies to manage the stress of caregiving, with "Act" being the most prevalent approach. Post-caregiving grief responses also vary significantly, with sub-themes including prolonged grief, anticipatory grief, irregular grief, and normal grief. Caregivers demonstrate a range of coping mechanisms during their caregiving journey, with a tendency towards active engagement ("Act") and strategic planning ("Plan"). After the caregiving period, grief responses vary from prolonged and anticipatory grief to more typical grieving patterns. These diverse experiences highlight the need for tailored support both during and after the caregiving period. It is recommended to develop and implement support programs that address the varied coping strategies and grief responses identified. During the caregiving phase, provide resources and workshops that focus on proactive planning and active engagement, offering practical tools and emotional support.

After the caregiving period, it is also suggested to create grief support services that cater to different grief sub-themes, including specialized support for prolonged and anticipatory grief. By offering personalized and empathetic interventions, practitioners can better address the unique challenges and emotional needs of caregivers at different stages of their journey.

4. Summary

The grief experiences of family caregivers after providing palliative end-of-life care are diverse and multifaceted. The analysis identifies four main grief sub-themes: prolonged grief, anticipatatory grief, irregular grief, and normal grief. Prolonged grief involves enduring mourning beyond typical timelines, while anticipatory grief reflects emotional preparation for impending loss. Irregular grief is characterized by intense, non-traditional grieving reactions, and normal grief represents more conventional responses to loss. These findings highlight the need for specialized support services that cater to the varied grief experiences of caregivers. It is recommended to develop targeted grief support programs that address these different sub-themes, offering personalized and empathetic interventions to help caregivers manage their unique emotional challenges. This approach will provide more effective support for caregivers as they navigate their grief and enhance their overall well-being.

Author contributions

Conceptualization, JEVB, RGRA, JKBCN, NVGP and LFMP; methodology, FCGE and MDKSS; validation and formal analysis, JEVB, RGRA, JKBCN, NVGP, LFMP, FCGE and MDKSS; investigation, JEVB, RGRA, JKBCN, NVGP and LFMP; resources and data curation, JEVB; original draft, handled the review and editing, JEVB, FCGE and MDKSS; visualization, supervision, and project administration, JEVB; administration, JEVB, FCGE and MDKSS. All authors have read and agreed to the published version of the manuscript.

Conflict of interest

The authors declare no conflict of interest.

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