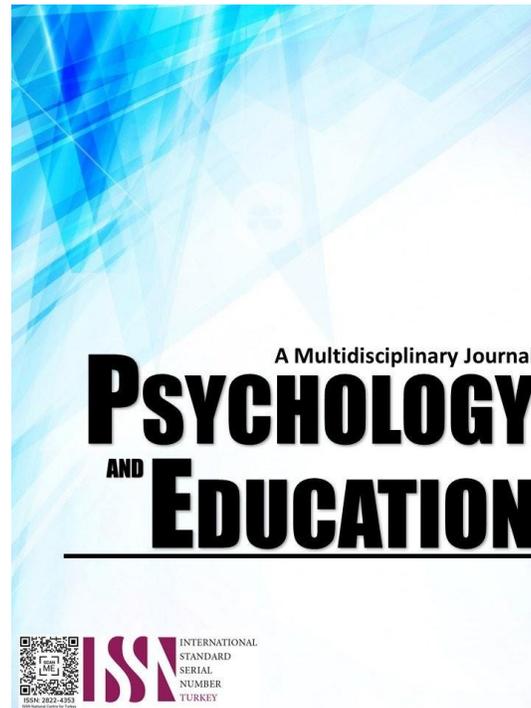


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Exploring Family Caregivers' Attachment, Adjustment, and Acknowledgement in Palliative End-of-Life Care

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Abstract

"Caring at the Crossroads" explored the experiences of family caregivers who provided palliative end-of-life care. The study employed a qualitative research design, combining a case study framework with a phenomenological approach. Thirteen participants, selected through purposive and snowball sampling, shared their firsthand experiences. The research method included interviews with the aim of capturing the subjective meanings, emotions, and attachment dynamics, particularly emphasizing the importance of secure attachments in providing stability, trust, and comfort during palliative care. It explored secure, anxious and fearful, and dismissive-avoidant attachment styles, revealing the emotional struggles and conscious choices made by caregivers. The adjustment processes of family caregivers involved a complex interplay of avoidance and approach behaviors. Freeze responses, characterized by hesitation and emotional immobilization, contrasted with flight responses, which involved emotional and physical withdrawal. Approach behaviors, marked by planning and action, demonstrated a proactive and committed approach to caregiving responsibilities. The study emphasized the need to recognize and respect the individual responses of caregivers in the palliative stage. It also acknowledged the various grief experiences that arose after palliative end-of-life care. The research identified four sub-themes: prolonged grief, anticipatory grief, irregular grief, and normal grief. These different patterns of grief highlighted the importance of personalized and empathetic support strategies to address the unique challenges faced by caregivers. The findings of this study provided valuable insights for psychology and counseling, offering understanding and empathy to those who navigated caregiving in the midst of love, pain, and resilience.

Keywords: *family caregivers, attachment, palliative care*

Introduction

Palliative end-of-life care is a crucial and sensitive phase in healthcare. Its focus extends beyond relieving the physical distress of individuals with life-limiting illnesses to addressing their complex emotional, social, and spiritual needs, as well as those of their families (NIH, n.d.). Family members play an essential role during this multidimensional journey, serving as primary caregivers, advocates, and emotional anchors for their loved ones. As psychology undergraduates, we are embarking on a compelling exploration of the psychological dimensions of family caregiving during this critical stage of life. Our study is driven by a shared commitment to applying our theoretical knowledge in psychology to a real-world context. We aim to understand the intricate interplay of psychological, emotional, and social dynamics involved in providing end-of-life care. Building on our academic pursuit of understanding human behavior, we seek to contribute valuable insights into the psychological aspects of palliative care. Our research not only fills gaps in existing literature but also informs future studies and interventions in this vital field. We firmly believe that comprehending the lived experiences of family members in palliative end-of-life care is crucial for developing comprehensive and compassionate care strategies. Steele and Davies (2015) highlight the pivotal role of family caregivers in shaping the quality of life for patients facing terminal illnesses. By delving into the nuanced aspects of caregiving, our study aims to identify demographic profiles, such as age, sex, the family member being cared for, the year of the member's death, family income, and the type of illness. This comprehensive understanding of diverse backgrounds will help shape caregiving experiences. Existing literature by Carlander et al. (2021), Martin et al. (2016), and Henriksson and Årestedt (2013) underscores the profound impact of caregiving on the well-being and self-identity of family caregivers. Preparedness emerges as a critical factor that enhances the coping mechanisms of family members (Carlander et al., 2021). Building upon these insights, our study aims to explore the multifaceted aspects of family caregiving before, during, and after the palliative stage. By identifying specific needs and challenges faced by family members, we aspire to contribute to the improvement of tailored support services and interventions in palliative care, based on a deep understanding of the psychological dimensions of caregiving. In our exploration of family caregivers' experiences, we draw inspiration from various research endeavors by Sercu et al. (2018), Hajradinovic et al. (2018), and Harrison et al. (2022), shedding light on the diverse modalities of palliative care. Our investigation encompasses the caregiving environment, the broader scope of end-of-life expectations, and the profound impact of caregiving on family caregivers' personal well-being. Aligned with our psychological exploration, we aim to contribute to the understanding of family caregivers' emotional responses, coping mechanisms, and the intricate dynamics that influence their experiences. By uncovering the psychological challenges inherent in providing palliative end-of-life care, our research strives to pave the way for tailored interventions that prioritize the mental health and well-being of family caregivers at the crossroads of caregiving.

Literature Review

In the landscape of palliative end-of-life care, family caregivers serve as the cornerstone of support, offering not only physical assistance

but also emotional and psychological comfort to their loved ones during their final journey. The research conducted by Carlander, Hellstrom, et al. (2021) sheds light on the intricate dynamics at play within the caregiver's psyche, revealing how the act of providing care can deeply impact their sense of self and overall well-being. This insight underscores the need for open and honest conversations surrounding the challenges and experiences encountered by caregivers, facilitating a supportive environment where they can express their concerns and seek assistance when needed. Moreover, Henriksson and Årestedt (2013) draw attention to the often-overlooked aspect of caregiver preparedness, highlighting the importance of equipping caregivers with the necessary skills and resources to navigate the complexities of providing palliative care.

The conceptual framework proposed by Sercu et al. (2018) offers a deeper understanding of the nuanced approach required in managing advanced chronic-progressive illnesses, where the emphasis shifts between life-preserving interventions and palliative care as the patient's condition evolves. This framework not only informs caregivers about the evolving needs of their loved ones but also guides healthcare professionals in tailoring care plans to best suit the patient's preferences and goals. Additionally, Hajradinovic et al. (2018) shed light on the significant influence of the caregiving environment on the overall experience of both caregivers and patients, highlighting the importance of creating supportive and comforting surroundings that promote dignity and quality of life.

As caregivers embark on the emotionally charged journey towards the end of life with their loved ones, the study conducted by Harrison, Darlison, and Gardiner (2022) underscores the critical role of adequate support and communication in preparing them for the inevitable challenges ahead. By fostering clear lines of communication between caregivers, healthcare providers, and patients, caregivers can feel empowered to make informed decisions and navigate the complexities of end-of-life care with confidence. However, as revealed by Odgers et al. (2018), the lack of open communication can hinder family involvement in decision-making processes, leaving caregivers feeling unprepared and isolated in their roles. Given these challenges, the findings of Van Eechoud et al. (2014) shed light on a potential solution. They suggest that promoting a collaborative approach to end-of-life care planning and decision-making can provide caregivers with the support in relation to their attachment, adjustment, and acknowledgment processes of providing palliative end-of-life care as they navigate towards their difficult but deeply significant journey.

Methodology

Research Design

This study employed a qualitative research design, seamlessly integrating a case study framework with a phenomenological approach to delve into the experiences of family caregivers in palliative end-of-life care. The case study design facilitated an in-depth exploration of unique instances, treating individual families as distinct cases. Simultaneously, the phenomenological approach served as a methodological lens, concentrating on the essence of lived experiences among family members providing palliative care. Through in-depth interviews, participant observations, and document analysis, this design aimed to capture the subjective meanings, emotions, and perceptions embedded in family caregivers' roles and the challenges encountered during the palliative care journey.

Participants

Thirteen participants, each with direct experience in palliative end-of-life care for their family members, were selected through purposive and snowball sampling methods. Purposive sampling ensured intentional selection based on characteristics pertinent to the research inquiry, while snowball sampling expanded the participant pool through referrals from initial participants. This dual strategy ensured a diverse and insightful participant group, contributing rich perspectives to the nuanced landscape of palliative end-of-life care within the familial context.

Instruments

Semi-structured interviews served as the primary data collection method, employing an aide memoire as the interview protocol. Crafted to elicit detailed narratives, the questions were designed to capture the emotional, social, and practical dimensions of family caregivers' experiences in the context of palliative end-of-life care. The flexible interview guide facilitated participants in expressing their unique perspectives while ensuring key themes were addressed consistently across interviews.

Procedure

The data gathering procedure employed face-to-face interviews, which helped create a comfortable and personal atmosphere that encouraged open communication. Through well-designed questions that covered various aspects, we were able to thoroughly delve into their caregiving journeys. By adapting our approach based on participant responses, we ensured a dynamic and organic exploration of topics, which accurately reflected the unique perspectives and challenges faced by each family.

Data Analysis

The data analysis phase employed a qualitative approach, incorporating Thematic Analysis and Content Analysis. Thematic Analysis identified recurring themes within the dataset, uncovering patterns and shared perspectives. Content Analysis, as a systematic research method, interpreted textual information, enriching the qualitative findings. These methods aligned with the study's overarching goal of exploring the psychological and emotional dimensions of palliative care provision, aiming to unveil challenges, coping mechanisms,

and variations in experiences among family caregivers.

Results and Discussion

Participants

The participants in our research exhibit a diverse demographic profile, representing a range of ages from 21 to 66 years. The caregiving roles assumed by participants include parents, grandparents, uncles, and a brother, illustrating the breadth of familial caregiving experiences within the scope of our study. The duration of caregiving spans from one month to eight years, underlining the temporal diversity of participants' engagements in providing palliative care. Noteworthy is the socioeconomic heterogeneity apparent in family incomes, varying from ₱5,000 to ₱90,000, reflecting the distinct financial backgrounds of our participants. Furthermore, the health conditions being addressed within the caregiving context are extensive, encompassing heart disease, liver sclerosis, pancreatic cancer, lung cancer, bone cancer, breast cancer, Alzheimer's, Parkinson's Disease, emphysema, and heart failure. This array of health conditions emphasizes the multifaceted challenges faced by family caregivers within the realm of palliative end-of-life care, laying a solid foundation for understanding the diverse experiences inherent in the provision of palliative care within a familial context.

Attachment

The decision to investigate attachment within the realm of family caregivers providing end-of-life care during the palliative stage was driven by a compelling curiosity surrounding the diverse and nuanced ways individuals experience emotional connections in the face of such challenging circumstances. Attachment, recognized for its profound impact on relationships, became a central focus of this study, as it was hypothesized to play a crucial role in shaping the experiences of those immersed in the complexities of palliative care. The rationale for exploring attachment styles was rooted in the acknowledgment that these patterns could significantly influence how individuals perceive, navigate, and cope with the demands of providing end-of-life care. The study aimed to unravel the intricacies of attachment by examining the major theme of "Attachment" and its associated sub-themes: "Secure," "Anxious and Fear," and "Dismissive-Avoidant."

The investigation unfolded with a comprehensive exploration of secure attachments, characterized by stability, trust, and comfort. Through qualitative analysis methods such as Thematic Analysis and Content Analysis, the study not only uncovered recurring themes within the dataset but also identified specific patterns, themes, and codes related to the experiences of family caregivers during the palliative stage. Content Analysis, a systematic research method, enabled the identification and categorization of specific patterns and themes within the data. The analysis revealed that the majority of participants exhibited a "Secure" attachment style, reflecting emotional stability and comfort in their relationships. This finding underscores the significance of secure attachments in fostering a sense of safety and stability, allowing individuals to be vulnerable and authentic in their caregiving roles.

Furthermore, the study delved into the sub-themes of "Anxious and Fear" and "Dismissive-Avoidant," providing a nuanced understanding of the struggles and conscious choices individuals make in their emotional connections during the palliative stage. The data derived from Content Analysis enriched the qualitative findings, offering a more detailed and comprehensive overview of the emotional landscapes within the studied cohort.

In essence, the investigation into attachment dynamics, supported by both Thematic Analysis and Content Analysis, was grounded in the belief that a deeper understanding of these patterns could not only contribute to the field of psychology and counseling but also inform targeted interventions to enhance the quality of support and connections within the intricate realm of palliative end-of-life care.

Adjustment

In delving deeper into the experiences of family caregivers during end-of-life care in the palliative stage, the thematic presentation brought forth a profound understanding of the intricate processes involved in adjustment. The major theme of avoidance and approach unfolded as a complex interplay, capturing the nuanced ways in which caregivers responded to the multifaceted challenges inherent in caring for their loved ones. The freeze response, emerging as a significant sub-theme under avoidance, offered a poignant glimpse into the emotional turmoil experienced by caregivers when faced with unexpected and distressing life events. The narratives vividly illustrated instances of hesitation, shock, and emotional immobilization, portraying a shared struggle to grapple with the abrupt and unpredictable nature of these pivotal moments.

Conversely, flight responses, manifested through emotional and physical withdrawal, revealed a diverse spectrum of coping mechanisms adopted by caregivers. From enduring emotional distress with stoic endurance to consciously avoiding direct confrontation with overwhelming information, caregivers demonstrated a range of strategies to navigate the complexities of their roles. This variability in flight responses emphasized the individualized nature of coping and highlighted the importance of recognizing and respecting these differences in the caregiving journey. Approach behaviors, as evidenced by planning and acting, showcased a proactive and committed orientation to caregiving responsibilities. Planning, characterized by a conscious determination of courses of action, illustrated caregivers' thoughtful and strategic approach to addressing the challenges they faced. Acting, on the other hand, reflected a deliberate and purposeful engagement in caregiving tasks, emphasizing the caregivers' hands-on involvement and initiative.

This in-depth exploration into the adjustment processes of family caregivers painted a comprehensive picture of their resilience and

adaptability. The narratives unfolded a rich tapestry of emotional, cognitive, and behavioral adjustments made by caregivers as they navigated the emotionally charged landscape of providing end-of-life care. The recognition of these diverse adjustment strategies is crucial for healthcare professionals and support networks to tailor assistance effectively, acknowledging and respecting the individualized responses of caregivers in the palliative stage.

Acknowledgement

The qualitative exploration of grief experiences following the provision of Palliative End-of-Life Care revealed valuable insights into the diverse ways individuals acknowledge and cope with the loss of their relatives. The major theme of "Grief" was dissected into four significant sub-themes: "Prolonged Grief," "Anticipatory Grief," "Irregular Grief," and "Normal Grief." Each sub-theme represented distinct patterns of emotional responses among the participants.

"Prolonged Grief" emerged as a sub-theme characterized by an enduring and persistent sense of mourning that surpassed conventional timelines. Two participants shared experiences marked by ongoing emotional pain, a void in guidance and support, and the lasting impact of grief even years after the loss. This sheds light on the necessity for sustained and specialized support tailored to the unique challenges associated with prolonged grief.

"Anticipatory Grief" was another sub-theme, revealing emotional challenges associated with anticipating an impending loss. Participants expressed a proactive emotional preparation for the loss, finding comfort in the belief that the departed loved one was no longer suffering. This highlights the nuanced nature of anticipatory grief and emphasizes the need for tailored interventions to assist individuals navigating the complexities of grieving before the actual loss occurs.

"Irregular Grief" surfaced from the narratives of four participants, showcasing unique and non-traditional expressions of grief that deviated from conventional norms. Intense and extreme reactions to loss, marked by observable shifts in behavior, were evident among these participants. This sub-theme emphasized the intricate and potentially conflicting set of coping mechanisms involved in irregular grief, necessitating understanding and support.

"Normal Grief" was the prevalent sub-theme, with five participants exhibiting a conventional and expected response to the loss experienced. The diverse array of emotional, physical, behavioral, and social dimensions of grief highlighted the complexity of this normal grieving process. Participants shared experiences of delayed tears, deep sadness, a sense of peace, and acknowledgment of the emotional pain associated with loss, all falling within the expected spectrum of normal grieving responses.

Overall, these sub-themes provided a nuanced understanding of the diverse ways individuals navigate the grieving process after providing Palliative End-of-Life Care. The insights gathered contribute to the fields of psychology and counseling, aiding practitioners in tailoring support and interventions to the varied needs of those undergoing the grieving process. The acknowledgment of prolonged, anticipatory, irregular, and normal grief experiences underscores the importance of personalized and empathetic support strategies in addressing the distinct challenges associated with each pattern of grief.

Conclusion

In our research study entitled "Caring at the Crossroads: An Exploration of Family Caregivers' Attachment, Adjustment, and Acknowledgement in Palliative End-of-Life Care", we delve into the profound experiences of family caregivers during the challenging palliative stage. Our diverse group of participants, aged 21 to 66, consists of individuals caring for parents, grandparents, uncles, and brothers, offering a rich tapestry of familial caregiving encounters for our exploration. Our primary focus is on unraveling the emotional dynamics at play in caregiving relationships.

Our research uncovered that secure attachments act as emotional anchors, providing stability, trust, and comfort to family caregivers amidst the demanding landscapes of end-of-life care. However, we also unearth sub-themes such as anxiety, fear, and dismissive-avoidant attachment styles, shedding light on the emotional struggles and conscious choices that arise as these family caregivers navigate the intricate interplay of love and loss. Additionally, we delved into the concept of adjustment, drawing parallels to the challenges faced by our participants—family caregivers. They navigate through moments of avoidance and approach, encountering freeze responses marked by emotional turmoil, hesitation, shock, and immobilization. Flight responses become apparent through emotional and physical withdrawal, showcasing the diverse coping mechanisms they employ in their personalized caregiving experiences. In contrast, approach behaviors, characterized by strategic planning and decisive actions, unveil the family caregivers' resilience and dedication in undertaking the substantial responsibilities associated with caregiving. Acknowledgment emerged as another significant theme in our study, unraveling the multifaceted layers of grief etched into the souls of our family caregiver participants. Prolonged Grief, extending beyond conventional timelines, demands sustained and specialized support. Anticipatory Grief serves as a silent prelude to loss, as these family caregivers prepare for the impending heartbreak. Irregular Grief highlights challenging and extreme reactions, while Normal Grief carries the weight of universal sorrow.

In conclusion, our study shows the tough experiences of family caregivers who provide end-of-life care. It's a hard journey, filled with pain and suffering. We hope our research helps people understand and empathize with caregivers. And we hope it leads to more support for them as they navigate the difficult path of caring for loved ones at the end of life.



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