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## Effect of Education and Policy on Informal Caregivers' Experience of Grief with End-of-Life Care

Brandan Margaret Rose  
*Walden University*

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# Walden University

College of Health Sciences and Public Policy

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Brandan Margaret Rose

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Walden University  
2024

Abstract

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Life Care

by

Brandan Margaret Rose

MPHIL, Walden University, 2023

MPH, Purdue Global University, 2021

BS, Purdue Global University, 2021

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Policy & Administration

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August 2024

## Abstract

While numerous studies have explored various aspects of end-of-life care, a significant gap persists in the literature regarding the emotional burden experienced by informal caregivers as they grapple with challenging decisions. Additionally, with current federal and state guidelines, administrators do not have clear policies to drive equity for patients and their informal caregivers. This qualitative study examined informal caregivers' perceptions of how end-of-life care policies impacted the dying process and how education influenced their grief and guilt. Using a conceptual framework of Simon's concept of bounded rationality and evidence-based policymaking, the study addressed constraints on caregivers' decision-making due to limited information, cognitive overload, and emotional stress. Data were collected through online surveys from 18 informal caregivers in the United States, exploring their experiences of grief and guilt and their recommendations to guide policy change for education on end-of-life care. Thematic analysis of survey transcripts revealed four themes: challenges with accessing and timeliness of support resources, psychological impact and enduring guilt, information and decision-making constraints, and hastening death? morphine-related guilt. Caregivers described facing significant emotional burdens, including guilt and grief, compounded by cognitive constraints, such as concerns about morphine in palliative care, fearing it might hasten death. This study advocates for positive social change through policies that improve support and resources for informal caregivers and highlights the necessity for educational initiatives to enhance caregivers' decision-making and emotional management within their cognitive limits.

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## Dedication

This dissertation is a heartfelt tribute to the extraordinary individuals who have been the guiding lights of my journey, infusing it with love, purpose, and unwavering support.

This dissertation is dedicated to my remarkable wife, MAJ Melissa Morehouse, an esteemed professor and an active-duty military spouse. Your dedication to education and service to our country is a testament to your resilience and strength. Your unwavering commitment, despite countless challenges, has been my constant source of inspiration. You've shown me that dedication, discipline, and transparency can lead to remarkable achievements. Your sacrifices have not gone unnoticed, and this dissertation is as much a reflection of your support as it is of my own efforts.

To my dear mother, Bernice, who left this world far too soon at the tender age of 56, I can only imagine how proud you would be today. At every step of this journey, I've carried your memory, determined to make you proud. Your presence, though physically absent, has been a driving force, reminding me of the importance of perseverance and ambition. As I embark on this academic milestone, I carry the torch of becoming the first Dr. Rose in our family, a tribute to my late grandparents, John Delbert Rose and Margaret Ann Rose. Mom, your legacy of hard work and determination lives on in me, and I dedicate this achievement to the memory of you.

I also wish to acknowledge Ann and George Moorehouse, who became the parents I needed when I needed them the most. To my sister Tammy, I adore you – because of you, your unconditional love for me, all of this was possible. My cousins

Karen and Desmond Ellie, whose tremendous support has been a beacon of patience and grace, your presence in my life has been invaluable. And to Pauline Wignall, who transformed my darkest days into a promise of brighter, more loving days through the gift of a beautiful, everlasting friendship.

To my three children, Kiara, Josh, and James, you have been the cornerstone of my journey, I love you so very much. To my grandchildren, may this dissertation serve as a precedent that can positively impact future generations. May it be a symbol for each of you, the importance of education, dedication, and the pursuit of knowledge.

This dissertation is a tribute to the love, support, and inspiration provided by my family, friends and colleagues. Thank you all for being an integral part of this emotional and deeply meaningful academic journey.

With all my love,

Dr. Brandan Margaret Rose

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## Chapter 1: Introduction to the Study

This study addresses a significant gap in the literature by examining the interplay between education, policy, and the grief processes of informal caregivers in end-of-life care. The primary motivation for this study stemmed from the scarcity of empirical evidence regarding how educational programs and policy measures might impact the emotional strain experienced by informal caregivers. By examining this intersection, I sought to contribute insights that can inform evidence-based policymaking and educational programming to reinforce support for informal caregivers. By offering an understanding of the challenges informal caregivers face and the factors shaping their grief experiences, this research illustrated the potential to inform targeted interventions tailored to the informal caregiver's unique needs. By informing how education and policy intersected with the informal caregivers' grief processes, policymakers could enact reforms to enhance informal caregiver support services, facilitate access to comprehensive end-of-life education, and enhance the quality of life for those experiencing support from informal caregivers. This societal shift can affect attitudes toward death, dying, and informal caregiving. By normalizing conversations surrounding end-of-life care and grief, a culture of empathy and support can be cultivated that honors the contributions of informal caregivers and prioritizes their emotional well-being.

### **Background**

While numerous studies have explored various aspects of end-of-life care (Skantharajah et al., 2022; Zapata et al., 2022), a significant gap persists in the literature regarding the emotional burden experienced by informal caregivers as they grapple with

challenging decisions. There was a need for supportive education and training materials on end-of-life choices to address this gap effectively (Martz & Morse, 2016; Stroebe et al., 2014). Notably, despite calls from several palliative care scholars for policy solutions and public education (Breen et al., 2020; Clarke & Seymour, 2010; Dittborn et al., 2021), there appeared to be a gap in the literature on public policy and administration on the need to provide end of life education to informal caregivers. The federal and state guidelines did not provide administrators with precise policies to drive equity for patients and their informal caregivers. This study was needed because there was a lack of clear guidelines and educational resources that ensured patients received appropriate care and alleviated unnecessary mental suffering for informal caregivers when making end-of-life decisions for their loved ones.

### **Problem Statement**

The specific research problem was the scarcity of evidence concerning the effects of end-of-life care education on informal caregivers' grief and guilt processes. There was insufficient understanding of how public policy and education addressed the informal caregivers' perceptions of end-of-life care and its implications for the dying process (Martz & Morse, 2016; Stroebe et al., 2014). Scholars have not examined the emotional toll on informal caregivers in navigating end-of-life decisions, and there was a noticeable gap in the literature regarding the specific link between policy provisions, education, consistency, and the grief and guilt experienced by these caregivers (Becker, 2023). Further, federal and state guidelines frequently lacked clarity and consistency, presenting challenges for public administrators and informal caregivers in understanding and



adhering to them (Becker, 2023). Priority should be given to policy reform aimed at bolstering accountability in the implementation of health policies and laws concerning the education of informal caregivers (Garcia, 2018; Vargas-Escobar et al., 2022). This directly impacts their experiences of grief and guilt surrounding end-of-life care (Clarke & Seymour, 2010). Additionally, there was a shortage of readily accessible educational resources tailored to meet the unique needs of informal caregivers (Zapata et al., 2022). Consequently, this study aimed to fill this gap by exploring the influence of policy and education on informal caregivers' experiences, particularly their feelings of grief and guilt within the context of end-of-life care.

### **Purpose of the Study**

The purpose of this generic qualitative study was to understand informal caregivers' perceptions of how policy on end-of-life care impacted the death and dying process and how education influenced their experience of grief and guilt by integrating evidence-based policymaking and Simon's bounded rationality theory. This research identified specific policy provisions that could effectively support caregivers during this emotionally demanding period, potentially leading to policy changes focused on education about end-of-life matters, fairness, and enhanced mental health support. Additionally, it examined caregivers' coping methods and investigated the impact of public policy frameworks on their emotional well-being, contributing to a deeper understanding of their psychosocial difficulties and the pivotal role of public policy in shaping their experiences.

The current literature underscored the relevance of investigating the impact of

policy on informal caregivers' grief and guilt in end-of-life care; informal caregivers, assisting dying loved ones, often undergo profound emotional stress and complex decision-making processes (Martz & Morse 2016). Existing federal and state policies lacked clarity, resulting in a demand for more targeted educational resources for these caregivers (Keser et al., 2022; Stroebe et al., 2014; Tilghman-Osborne et al., 2010). A significant gap in research related to how policy provisions directly influence informal caregivers' grief and guilt experiences. This gap highlighted the need for policy reform, enhanced health policy accountability, and the administration to better support informal caregivers (American Association of Psychiatry, 2023).

### **Research Question**

What do the grief and guilt experiences of informal caregivers reveal that would guide policy change for education on end-of-life care?

### **Conceptual Framework**

The conceptual framework of this study drew upon the interplay between Simon's bounded rationality theory and evidence-based policymaking, which provided a comprehensive understanding of how policy reform could positively impact end-of-life care for informal caregivers. Simon's (1957) theory posits that individuals are constrained by cognitive limitations when making decisions, with factors such as available information, cognitive capacity, and time constraints influencing their choices. Applied to the context of end-of-life care for informal caregivers, this theory highlighted caregivers' cognitive challenges due to emotional stress, lack of knowledge, and time constraints. Acknowledging these constraints is crucial for policymakers and healthcare

professionals to design tailored interventions and policies that cater to the needs of informal caregivers (Phillips et al., 2020). By recognizing and integrating these cognitive limitations into policy design, policymakers can develop more realistic and effective strategies that align with caregivers' capabilities (Berwick, 2003; Schaathun, 2022; Ward et al., 2009).

Evidence-based policymaking involves utilizing the best available research evidence to inform decision-making processes, ensuring policies are grounded in scientific evidence rather than subjective opinion or political bias (Davies et al., 2000). In end-of-life care for informal caregivers, evidence-based policymaking holds promise for enhancing the quality of care and support provided to caregivers (Berwick, 2003; Ward et al., 2009). By incorporating research findings into policy development, policymakers can address various caregiver needs, including access to resources, psychological support, and educational programs (Berwick, 2003; Schaathun, 2022; Ward et al., 2009).

Furthermore, evidence-based policymaking can identify research gaps and guide future studies to address specific caregiver needs, potentially reducing the likelihood of prolonged grief (Martz & Morse, 2016). Bridging the gap between research and policymaking presents an opportunity to improve policies surrounding end-of-life care for informal caregivers (Keser et al., 2022; Stroebe et al., 2014; Tilghman-Osborne et al., 2010). By integrating Simon's bounded rationality theory with evidence-based policymaking, policy reform initiatives can be developed to acknowledge caregivers' cognitive limitations, address their unique needs, and provide appropriate support during the challenging period of end-of-life care. Chapter 2 further explores how Simon's theory

recognizes caregivers' cognitive limitations and informs policymakers to craft realistic policies (Simon, 1957). Additionally, the review scrutinizes how evidence-based policymaking ensures decisions are firmly grounded in research, enhancing support for informal caregivers and improving the quality of end-of-life care (Brownson et al., 2018).

### **Nature of the Study**

To explore the research question guiding this qualitative study, the research design was a generic qualitative approach, with thematic analysis following Braun and Clarke's (2021) process and then incorporating Saldaña's (2016) descriptive coding processes first and second-cycle coding. The chosen design enabled me to delve into the experiences of informal caregivers during end-of-life care, aligning with the study's focus on understanding the impact of education and policy on grief and guilt processes. This approach centered on investigating participants' engagement with education, policy, and caregiver experiences in end-of-life care and uncovered how these elements influence grief and guilt among caregivers. Data collection involved interacting with informal caregivers through a researcher-created web-based qualitative survey that captured their lived experiences and perspectives. Thematic analysis was utilized to identify and interpret patterns and themes related to education, policy, grief, and guilt, which provided insights into caregiver experiences and informed potential policy and educational interventions that enhance caregiver support in end-of-life care scenarios (Saldaña, 2016).

### **Definition of Terms**

*Comfort care:* A holistic approach to care that prioritizes the physical, emotional, and spiritual comfort of patients, particularly those facing life-limiting illnesses. Comfort

care may encompass palliative and hospice care elements, focusing on symptom management, pain relief, and enhancing quality of life (Kolcaba & Fisher, 1996).

*Education on end-of-life care:* Formal or informal programs, resources, and interventions designed to provide caregivers with knowledge and skills related to end-of-life care, including medical procedures, communication strategies, and coping mechanisms for those who are in the final stages of a terminal illness or nearing the end of their life (Izumi et al., 2012).

*Formal care:* Home health aides who are paid for their professional services. (Roth et al., 2015).

*Grief:* The emotional response to loss, including feelings of sadness, longing, and mourning experienced by caregivers following the death of their loved one (The American Association of Psychiatry, 2023).

*Guilt:* The emotional response characterized by feelings of responsibility, regret, or self-blame (Tilghman-Osborne et al. 2010).

*Hospice:* A type of palliative care specifically tailored to individuals who are nearing the end of life, typically with a prognosis of six months or less to live. Hospice care emphasizes comfort and dignity, alleviating physical, emotional, and spiritual suffering for patients and their families (McCabe, 1982).

*Informal care:* Being a person who provides some type of unpaid, ongoing assistance with activities of daily living (ADLs) or instrumental activities of daily living (IADLs) to a person with a chronic illness or disability (Roth et al., 2015).

*Palliative care:* Specialized medical care focused on providing relief from

symptoms, pain, and stress associated with a serious illness, with the goal of improving quality of life for both patients and their families. Palliative care can be provided alongside curative treatment and is not limited to end-of-life care (Van Mechelen et al., 2013).

### **Assumptions**

In this study, critical assumptions were made that underpin the meaningfulness of the research. The first assumption was that the participants would respond honestly to inquiries about their caregiving experiences. The duty fell upon the researcher to delve into the meanings expressed by participants rather than presuming a shared understanding (Walker, 2015). Furthermore, it is assumed that participants' contributions, including their narratives during the survey, are truthful representations of their experiences (Vaismoradi et al., 2016). These assumptions were necessary to ensure the credibility and validity of the study's findings, as they formed the basis for understanding informal caregivers' nuanced challenges and perspectives. Another assumption was that the survey instrument would sufficiently capture participants' perspectives and enable them to articulate their lived experiences (Yazan, 2015). Additionally, there was an assumption that my data analysis minimized biases to safeguard impartiality in interpreting and coding the data (Cho & Lee, 2014). While these assumptions could not be definitively demonstrated to be true, they were essential for guiding the research process and interpreting the findings within the study's limitations.

### **Scope and Delimitations**

The scope of the study was focused on informal caregivers' experiences with grief

and guilt in the context of end-of-life care, specifically examining how education and policy interventions influenced these processes, which was different from formal caregivers (Shiba et al., 2016). By concentrating on informal caregivers, the study ensured depth and specificity in exploring their unique perspectives and needs during the end-of-life care journey. However, the study deliberately excluded formal caregivers and healthcare professionals, as their roles and support systems differ significantly from those of informal caregivers (Shiba et al., 2016).

The delimitations of the study were outlined to establish boundaries and focus (Elis, 2009). While the research centered on education, policy, and grief and guilt processes, it did not delve into broader aspects of caregiving dynamics, such as coping mechanisms or attachment theory, which could provide additional insights (Strobe, 2005). Moreover, the study's scope did not extend to examining the implementation of specific policy interventions or educational programs but rather aimed to understand their potential impact on informal caregivers' emotional experiences. The study delineated its boundaries and focus, primarily exploring the impact of education and policy on informal caregivers' grief and guilt processes. However, it did not explore broader caregiving dynamics or the implementation of specific interventions (Elis, 2009; Strobe, 2005).

### **Limitations**

It was important to recognize certain design and methodological weaknesses that could impact the overall validity and reliability of the findings when reviewing the study's limitations. One significant limitation lies in the qualitative approach utilized. While a generic qualitative approach offered rich insights into informal caregivers'

perceptions, it may have lacked the precision and generalizability of more structured methodologies, thus posing a limit on transferability. Qualitative research inherently involved subjectivity and interpretation, potentially limiting the transferability of findings to other contexts (Patton, 2015). The reliance on participants' self-reports introduced the possibility of social desirability bias, where respondents may provide answers they believe are socially acceptable rather than reflecting their true experiences (Babbie, 2016). Additionally, there might have been recall bias, as informal caregivers may not have accurately recalled their emotions and experiences over time, particularly during emotionally charged periods (Ranse, 2016).

To mitigate these biases and limitations, several measures were implemented. First, ensuring a diverse sample of informal caregivers from various demographic backgrounds enhanced the study's representativeness and broadened its applicability (Patton, 2015). Additionally, the consistent maintenance of journaling and expert peer review notes throughout the research process identified and mitigated potential biases stemming from the researcher's perspectives and assumptions (Creswell & Creswell, 2017).

### **Significance**

This study was significant in that it has the potential to fill a gap in the literature on public policy and administration by concentrating on the effect of public policy on the informal caregiver's experience of grief and guilt with end-of-life care. The findings of this study were expected to contribute to social change by illuminating the scarcity of public policy that addresses how the perceptions of end-of-life care affect the informal



caregiver's experience of grief. The results may provide insights into how the policies can be specified and improved.

### **Summary**

This chapter introduced this research into the importance of informal caregiving, which improved understanding of how education influenced caregivers' grief and guilt experiences and how policy impacted the death and dying process. Using a generic qualitative method and in-depth surveys, I explored the interplay between education and emotional distress among informal caregivers. The research problem focused on the insufficient evidence regarding education's effects on caregivers' grief and guilt (Arbour & Wiegand, 2016). The study aimed to identify policy changes to support caregivers better and reduce distress, guided by theoretical frameworks like Simon's bounded rationality theory and evidence-based policymaking. Finally, the chapter discussed assumptions, scope, and limitations, setting the stage for a comprehensive exploration of the interplay between education, policy, and caregivers' grief experiences, with implications for positive social change. The following chapter delves into a comprehensive review of existing literature pertaining to the research phenomenon, aiming to offer a rationale for undertaking this study.

## Chapter 2: Literature Review

This chapter explores the current body of literature on how policies impact the emotional journey of informal caregivers when it comes to providing end-of-life care. The analysis explores the relationship between public policy, informal caregivers' emotional well-being, and end-of-life care's complexities. Through a careful analysis of the literature, the main objective of this chapter is to shed light on the gaps in current knowledge, identify limitations in existing policies, and illustrate the rationale for conducting the study.

### **Literature Search Strategy**

The literature review contains research relevant to the study's focus on the effect of policy on informal caregivers' experience of grief and guilt with end-of-life care. To ensure a rigorous and thorough examination, an exhaustive search was conducted across various databases, namely Ebsco, Medline, Elsevier, Google Scholar, National Institutes of Health, US Department of Health and Human Services, Centers for Medicare and Medicaid Services, World Health Organization, APA PsycInfo, Palliative Medicine, Academic Search Complete, and PubMed. The selected keywords used for the search encompassed topics related to the study, including *Morphine*, *Health Policy*, *Aging Policy*, *Policy Administration*, *Policy Analysis*, *Terminal Care Laws*, *Decision Making*, *Federal Legislation*, *Informed Consent*, *Health Disparities*, *Informal Caregivers*, *Policy*, *Bureaucracy*, *Grief*, *Education*, *Misperception*, *Death*, *Mental Health*, *end of life*, and *programs*. This strategic approach allowed me to acquire an extensive body of literature. It contributed to a holistic understanding of the policy landscape and policy factors

affecting the informal caregivers' experience of grief with end-of-life care.

## **Conceptual Framework**

### **Simon's Bounded Rationality Theory**

Nobel Laureate Herbert Simon introduced the concept of bounded rationality as a critique of traditional models that presuppose human beings as perfectly rational entities capable of processing unlimited information for optimal decision-making (Hasani, 2019). Simon contended that cognitive restrictions, such as finite memory and computational capacity, hinder people from achieving perfect rationality (Hassani, 2019; Schaathun, 2022). Instead of seeking optimal solutions, individuals often resort to heuristics or satisfying strategies that yield sufficiently acceptable outcomes within given constraints (Fiori, 2009). Hasani (2019) further enriched this discussion by underlining the cognitive complexities that circumscribe human decision-making.

### **Evidence-Based Policymaking**

Evidence-based policymaking (EBPM) has emerged as a rigorous approach that privileges empirical data in formulating and implementing policies. Originating in the healthcare sector, this methodology has gained traction across diverse domains such as education, criminal justice, and social policy (Duke, 2001). At its core, EBPM argues for the construction of policy based on robust scientific evidence rather than subjective beliefs or political biases (Davies et al., 2000).

### **Simon's Bounded Rationality Theory and EBPM**

The current discourse amalgamates Simon's bounded rationality theory with the principles of EBPM, focusing on their applicability to end-of-life caregiving. Bounded

rationality, particularly in the stressful and time-sensitive context of end-of-life caregiving, provides valuable input for creating empathetic and effective policies (Schaathun, 2022). Similarly, EBPM contributes by grounding such policies in a solid foundation of empirical data, thus enhancing the care quality provided to informal caregivers (Berwick, 2003; Ward et al., 2009). Moreover, EBPM can facilitate a seamless interface between academic research and policy formulation, thereby encouraging a cycle of continuous policy innovation (Phillips et al., 2020).

Several empirical studies substantiate the relevance of these theoretical frameworks for policy development and caregiver interventions. Schaathun (2022) stressed the importance of adaptability and cross-disciplinary perspectives, mirroring Simon's emphasis. On the other hand, Ward et al. (2009) and Berwick (2003) highlighted the value of knowledge dissemination and evidence-led decision-making. There are challenges in the policymaking process, especially in sifting through academic literature for credible evidence (Phillips et al., 2020). In end-of-life care, diverse studies validate the potential of these frameworks to influence policy positively. These range from calls for policy and administrative reform (Schulz et al., 1997) to the effectiveness of evidence-based interventions on caregiver outcomes (Campbell et al., 2021; Jo et al., 2023). Likewise, data-driven decision-making and large-scale evaluations are significant (Ndoungue et al., 2022; Thrower et al., 2023).

To summarize, consolidating Simon's bounded rationality theory with EBPM offers an approach to crafting policies to aid informal caregivers in end-of-life care (Berwick, 2003; Schaathun, 2022; Ward et al., 2009). By acknowledging the cognitive

limitations intrinsic to caregiving scenarios and leveraging empirical evidence, policy designers can formulate well-crafted strategies to address the complex landscape of caregiving (Berwick, 2003; Schaathun, 2022; Ward et al., 2009). Literature substantiates the value of iterative feedback loops between research and policy, furthering policy innovations that benefit informal caregivers navigating grief and caregiving (Phillips et al., 2020).

### **Literature Review Related to Key Concepts**

This comprehensive literature review focuses on the various interconnected aspects surrounding informal caregivers' experiences in the context of end-of-life care. The exploration begins by delving into the influence of public policy and education on the emotions of grief and guilt that informal caregivers grapple with. Additionally, the historical evolution of health policy concerning end-of-life care is examined, along with an in-depth analysis of existing federal and state policies and the role of informal caregivers. Furthermore, I explore the intricate challenges that informal caregivers face in providing long-term care. I highlight the notable gaps in the current body of literature, which emphasizes the significance of policy solutions and public education. Then I provide a comparative synthesis of end-of-life care health policies in the United States, Canada, and Germany. Through this exploration, the aim was to shed light on the multifaceted dimensions of informal caregivers' experiences in end-of-life care, with a focus on policy, education, and emotional well-being.

### **Understanding Grief**

The American Association of Psychiatry (2023) defined grief as a complex

emotional journey encompassing various emotional struggles, existential questioning, and hidden pain, known as *disenfranchised grief*. It can significantly impact physical and mental well-being, including effects on the immune system and potential thoughts of suicide, highlighting the importance of specialized mental health interventions (American Association of Psychiatry, 2023). It is important to have skilled behavioral health specialists in hospice settings; these specialists play a crucial role in providing grief counseling, although their expertise may differ from one setting to another (Becker, 2023). Personalized and compassionate care is necessary, especially in the context of informal caregivers grieving during end-of-life situations (Becker, 2023). It has also been indicated that preparing for an anticipated loss can serve as a safeguard against negative psychological consequences, such as pre-loss grief and prolonged grief disorder (Singer & Papa, 2021; Zapata et al., 2022). However, additional investigation is required to fully understand the preparedness framework in the context of individuals who have loved ones with life-limiting illnesses and its relationship with pre-loss grief (Singer & Papa, 2012).

The body of research consistently underscores the importance of understanding and supporting informal caregivers throughout their grief journey to enhance their overall well-being (Brand et al., 2016; Breen et al., 2020; Schulz et al., 1997). When caregivers experience emotional overload during the grieving process, it can lead to them feeling marginalized and socially isolated (Bindley et al., 2022). This highlights the importance of having a more comprehensive understanding of the various factors that contribute to vulnerabilities (Skantharajah et al., 2022), emphasizing the significance of recognizing

systemic obstacles and social inequalities as well (Bindley et al., 2022). It is important to recognize the connection between public policy and the emotional aspects of caregiving. A multi-disciplinary approach combining public policy considerations and healthcare practices can significantly improve end-of-life caregiving's emotional and practical aspects.

### **Conceptualizing the Experience of Grief and Guilt in End-of-Life Care for Informal Caregivers**

Guilt can be a complex experience, especially when caring for others and dealing with end-of-life situations; several studies have shown that guilt can have a significant effect on caregivers, family members, and those involved in end-of-life care (Keser et al., 2022; Martz & Morse, 2016; Stroebe et al., 2014; Tilghman-Osborne et al., 2010). In their study, Stroebe et al. (2014) explored the differences between self-blame and regret in grieving. They examined how guilt and bereavement are intertwined and found that self-blame is particularly prominent in the initial stages of grief; however, it also changes and develops separately as time goes on. The importance of personalized interventions for caregivers involved in end-of-life care is highlighted by this discovery (Stroebe et al., 2014).

In their study, Martz and Morse (2016) delved into the emotional impact of treatment decisions for parents nearing the end of their lives, further expanding the conversation around familial caregivers. The research showed that families frequently face moral dilemmas, especially when they have to make choices that might accelerate the passing of a family member. According to Martz and Morse (2016), the emotional

impact of this situation highlights the importance of implementing specific policies and educational programs.

Tilghman-Osborne et al. (2010) conducted an in-depth analysis to elucidate the concept of guilt by examining variations in its definitions within prior research. Their findings revealed that guilt is a multifaceted construct encompassing emotional and cognitive dimensions, laying a solid foundation for further investigations. Notably, the theoretical framework established in their study holds significant implications for policies and educational strategies pertaining to caregivers (Tilghman-Osborne et al., 2010). In a different vein, Joa and Newberg (2021) contributed valuable insights by shedding light on the intricate relationship between guilt and Prolonged Grief Disorder (PGD). Their research highlighted the often-neglected positive facets of guilt and its interplay with grief and PGD, enriching our comprehension of this subject. Additionally, Keser et al. (2022) delved into psychoanalytic theories surrounding guilt in the context of bereavement. Their investigation uncovered the role of guilt in bridging pre-death conflicts and unhealthy grieving processes, underscoring the intricate emotional terrain navigated by caregivers and advocates when dealing with targeted policy frameworks.

Guilt, a multifaceted and pivotal emotion in the context of end-of-life care for caregivers, was extensively examined (Keser et al., 2022; Martz & Morse, 2016; Stroebe et al., 2014; Tilghman-Osborne et al., 2010). Studies emphasized its significant impact on caregivers, family members, and those engaged in end-of-life care. Stroebe et al. (2014) distinguished between self-blame and regret, revealing their evolution and highlighting the need for personalized interventions. Martz and Morse (2016) delved into the



emotional consequences of treatment decisions for terminally ill parents, emphasizing the moral dilemmas families face and advocating for specific policies and education. In contrast, Tilghman-Osborne et al. (2010) defined guilt as a complex concept encompassing emotional and cognitive aspects, shaping the groundwork for policy and education. Joa and Newberg (2021) explore guilt's connection to Prolonged Grief Disorder, revealing its overlooked positive aspects, and Keser et al. (2022) relate guilt to pre-death conflicts and unhealthy grieving processes within targeted policy frameworks. These findings collectively underscore guilt's profound influence, necessitating tailored policies and education for caregivers in end-of-life care.

Guilt is a complex and significant emotional experience for caregivers, particularly those involved in end-of-life care (Martz & Morse, 2016), and the conceptual lens used for this study provides a holistic perspective on how guilt manifests in caregiving and end-of-life situations. According to the American Psychological Association (2023), guilt is described as an emotional state where individuals assess themselves and experience distress, often feeling compelled to make amends for perceived mistakes. The complex connection between grief and emotional well-being deserves careful examination (Keser et al., 2022; Tilghman-Osborne et al., 2010). Stroebe et al. (2014) asserted that it is crucial to implement specific public policies and educational programs to tackle these issues of guilt and grief effectively.

Grief is a complex experience involving a wide range of emotional, cognitive, physiological, and behavioral reactions that occur after experiencing a significant loss (PDQ Supportive and Palliative Care Editorial Board (2022). In 1969, Elisabeth Kübler-

Ross contributed significantly with her influential book “On Death and Dying.” Her work introduced the widely recognized five-stage model of grief, which has been a valuable resource for clinicians and scholars. However, it is crucial to consider the evolving theoretical frameworks. In end-of-life care, the Dual Process Model by Stroebe and Schut (1999) offers a valuable perspective on grief, distinguishing between loss and restoration stressors. It introduces “oscillation” as a coping mechanism. While previous research has explored the complex emotions of grief and guilt in caregiving (Martz & Morse, 2016; Stroebe et al., 2014), a notable gap exists in understanding how end-of-life care education impacts informal caregivers’ grief and guilt. Given the intricate nature of caregiving emotions, it is crucial to consider the Dual Process Model and conduct further research on educational policies’ potential to alleviate caregivers’ emotional burdens in end-of-life care.

By analyzing Academic Perspectives to Define End-of-life Care, building upon the diverse viewpoints presented by Hui et al. (2012), Mauck (2022), and the World Health Organization (2023), we can gain a deeper understanding of how public policy influences the emotional well-being of informal caregivers in end-of-life situations by exploring the significance of end-of-life care. In Hui et al.’s (2012) study, they delve into terminology variability in palliative and supportive oncology; their findings highlight that the lack of standardized definitions is a minor concern in academia and a multifaceted issue with significant implications in the real world. Their discoveries align with how the healthcare system and policy frameworks can be understood and implemented. Hui et al. (2012) noted that the differences in terminology can create confusion within institutions,

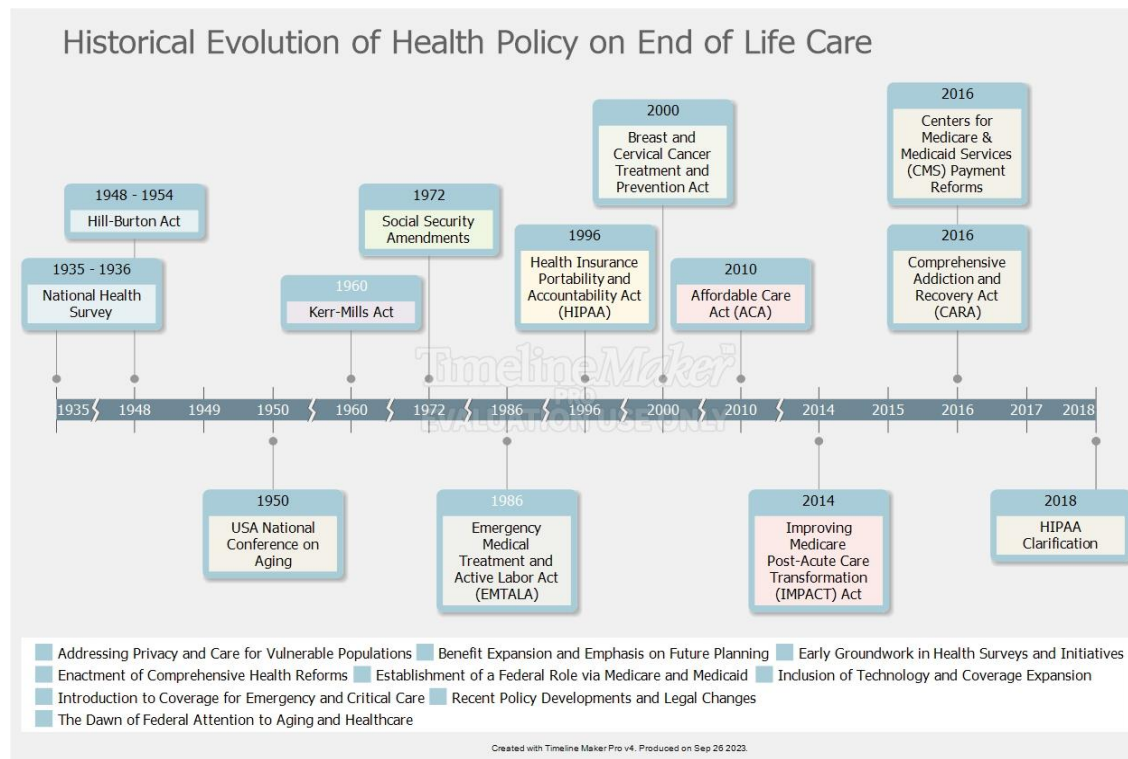
which could affect policy decisions meant to support informal caregivers. In their study, Hui et al. (2012) provided insights into the potential impact of these ambiguities, highlighting how these uncertainties can hinder the use of services, create obstacles in translating academic knowledge into practical care, and introduce variability that can impact the reliability of clinical trials and systematic reviews.

Mauck (2022) expands on this viewpoint by exploring the practical aspects of providing care at the end of life. The five-element framework he developed, which includes diagnosis, timeframe, type of care, location of care, and future planning, provides a more detailed perspective on end-of-life care. When used in policy analysis, Mauck's individualized approach provides a practical perspective for assessing how regulations may affect informal caregivers differently (Mauck, 2022). For example, recognizing the significant differences in the type of care provided in home-based palliative setups versus institutional hospice care could help policymakers create more inclusive and adaptable caregiving policies.

The World Health Organization's ethical imperative of universal access to palliative care is a critical perspective to consider (World Health Organization, 2023). It highlights the importance of ensuring everyone has access to palliative care; in the broader perspective, it highlights the moral duty of governments and international organizations to guarantee that palliative care is not seen as a luxury but a fundamental human right. From a policy perspective, this proposal brings forth a universal standard that encourages the healthcare system to prioritize inclusivity and ethics. The World Health Organization's concerning statistic reveals that only 14% of people who require

palliative care receive it, highlighting the importance of addressing this ethical obligation, especially for informal caregivers who often face the emotional and ethical challenges of dealing with an inadequate system (McKibben et al., 2020).

Combining these academic perspectives results in a comprehensive framework for analyzing policies, which provides a multi-level, multidimensional structure for comprehending end-of-life care. This framework provides a comprehensive approach to understanding how policies can impact and address the multifaceted needs and ethical challenges informal caregivers face. Considering this perspective, policymakers and educators can develop policies that integrate clinical knowledge, as proposed by Hui et al. (2012), personalized to individual needs, as emphasized by Mauck (2022), and grounded in ethical principles, as advocated by the World Health Organization (n.d.). It is crucial to devise policies that account for informal caregivers' emotional, ethical, and practical challenges in end-of-life situations. Addressing these complexities effectively requires a multidimensional approach. The Historical Evolution of health policy on the end-of-life care diagram, seen in Figure 1, illustrated the changes and advancements in health policy regarding end-of-life care over time.

**Figure 1***Historical Evolution of Health Policy on End-of-Life Care*

Although not explicitly centered on end-of-life care, the National Health Survey conducted between 1935 and 1936 was crucial in establishing data collection techniques that would enhance research on patient experiences (Wolff, 2007). The emergence of health legislation in the post-war period has been a significant development in public health from 1948 to 1954; the Hill-Burton Act, while designed initially without specific consideration for end-of-life care, indirectly contributed to the increased accessibility of these services. The actions above were undertaken by providing financial support for hospital infrastructure development and implementing policies to prevent discrimination within healthcare environments (Brinker & Walker, 1962; Thomas, 2006). The

emergence of the federal government's attention toward aging and healthcare becomes evident. The 1950 USA National Conference on Aging was a significant nationwide initiative focused on the aging population; given the intricate healthcare requirements of older individuals, this event holds particular importance for end-of-life care (The National Conference on Aging, 1950).

Establishing Federal Assistance through Medicare and Medicaid was primarily impacted by the 1960 Kerr-Mills Act, a piece of legislation that aimed to provide federal financial aid to states to support healthcare services for the elderly demographic. One of the indirect outcomes of this act was the provision of end-of-life care, which was facilitated through programs such as Medicaid and the Children's Health Insurance Program (CHIP). This act played a significant role in ensuring adequate healthcare services were available for elderly individuals nearing the end of their lives. (Medicaid and CHIP Payment and Access Commission, 2023).

While expanding the Scope of Advantages and Strategizing for Long-Term Development, the 1972 Social Security Amendments broadened Medicare coverage to encompass individuals under 65 who suffer from chronic illnesses and end-stage renal diseases. This expansion effectively increased the population eligible for federally funded end-of-life care services (Weinstein, 1978). The topic of discussion pertains to the evolution of emergency and critical care coverage. The 1986 Emergency Medical Treatment and Active Labor Act (EMTALA) significantly impacted end-of-life situations as it mandated emergency medical interventions. This, in turn, affected the context in which informal caregivers carry out their duties (see "United States Arbitration Act Held

to Create Federal Substantive Law Applicable in Both State and Federal Courts,” 1960).

Ensuring the Privacy and Security of At-Risk Communities The Health Insurance Portability and Accountability Act (HIPAA) of 1996 was enacted to protect medical records’ confidentiality. Its provisions have significantly impacted end-of-life care’s decision-making and communication processes (Kulynych & Korn, 2003). Technological inclusion refers to the extent to which individuals and communities have access to and can effectively utilize various forms of technology. This encompasses physical access to devices and infrastructure and the ability to navigate and utilize digital platforms and services coverage extent.

The 2000 Breast and Cervical Cancer Treatment and Prevention Act has significant implications for end-of-life care as it permits Medicaid to provide coverage to certain women diagnosed with breast and cervical cancer (“Medicaid Expansion Under the Affordable Care Act,” 2013). The 2003 Medicare Modernization Act, also called Medicare Part D, played a crucial role in making medications more affordable and accessible, particularly for individuals receiving end-of-life care with a focus on palliative purposes (Medicaid Expansion Under the Affordable Care Act, 2013).

The implementation of comprehensive reforms in health policies has emerged as a crucial area of focus in recent years. The 2010 Affordable Care Act (ACA) significantly impacted end-of-life care by prioritizing patient-centered approaches and promoting improved collaboration among healthcare providers (Medicaid Expansion Under the Affordable Care Act, 2013). The 2014 Improving Medicare Post-Acute Care Transformation (IMPACT) Act was implemented to establish uniform patient needs

assessments in different post-acute care environments. This had a significant impact on the smooth transitions within end-of-life care frameworks, as highlighted in “The Affordable Care Act (ACA) in the Past Decade” (2020).

### **Current Policy and Legislative Developments**

The payment reforms implemented by the Centers for Medicare & Medicaid Services (CMS) in 2016 aimed to humanize the healthcare system while maintaining an academic approach. The reforms mentioned above-implemented payment structures incentivizing healthcare providers to initiate discussions regarding end-of-life choices with their patients (Medicaid Expansion Under the Affordable Care Act, 2013). The Comprehensive Addiction and Recovery Act (CARA) of 2016 was enacted to address the issue of addiction comprehensively and promote recovery. The main focus of this legislation was addiction, but it also had secondary effects on end-of-life care by placing importance on pain management (Congress 2014).

The 2018 Right to Try Act granted terminally ill patients the option to pursue experimental treatments, which presented ethical challenges while expanding the range of decisions available to individuals nearing the end of their lives (Agarwal & Saltz, 2020). The 2018 update to the Health Insurance Portability and Accountability Act (HIPAA) introduced clarifications regarding healthcare providers’ sharing of medical information with family members actively involved in patient care. This modification aimed to enhance communication during end-of-life situations (Cohen, 2018).

### ***Federal Policies***

The U.S. Department of Labor (2023) states that the Family and Medical Leave



Act (FMLA) permits qualified employees to take a maximum of 12 weeks of unpaid leave over 12 months to care for a seriously ill family member, even in end-of-life situations. The Older Americans Act (OAA) is a legislation that provides funding and support for a range of services aimed at assisting caregivers of older adults, including those who are in the final stages of life. These services include respite care and caregiver support services. The OAA is crucial in ensuring caregivers have the resources to provide quality care for older adults. The National Family Caregiver Support Program (NFCSP) is a component of the OAA that offers grants to states. These grants help states provide various supportive services to informal caregivers of older adults. These services include counseling, respite care, and training. In addition, federal healthcare programs like Medicare and Medicaid offer coverage for specific end-of-life care services. One such service is hospice care, which supports patients and their caregivers during the final stages of illness (U.S. Department of Health and Human Services, 2023). State policies are crucial in supporting caregivers, as they offer various Medicaid waivers that provide additional assistance and services.

These waivers can include valuable resources like respite care and home-based services, significantly contributing to caregiver support. In addition, numerous states have implemented respite care programs that offer caregivers temporary relief and enhance their support initiatives. These programs provide valuable resources, education, and services to caregivers. Furthermore, per the U.S. Department of Health and Human Services, state-funded home and community-based services are crucial in easing caregiving responsibilities for individuals with severe illnesses (2023). The laws

regarding Advance Directives that vary from state to state can notably influence how caregivers support their loved ones in such situations. In the grand scheme of things, both federal and state policies have a significant impact on assisting informal caregivers during end-of-life care. These policies offer vital services and resources to support caregivers in their essential roles, ultimately enhancing end-of-life care for patients across the United States.

### ***State Policies***

State policies concerning informal caregiver support vary across the United States, encompassing a range of initiatives. Some states offer Medicaid waivers, granting additional support and services to caregivers, such as respite care and home-based services (Colello, 2007). In several states, respite care programs have been established to provide caregivers with short-term relief, allowing them to take a break from their caregiving responsibilities. Furthermore, certain states have developed caregiver support initiatives, offering resources, education, and services to informal caregivers (Colello, 2007). Additionally, states may implement programs that provide home-based care and support for individuals with serious illnesses, easing some caregiving burdens. Notably, state-specific Advance Directive laws concerning advance care planning, medical power of attorney, and other end-of-life decision-making tools can significantly influence how caregivers assist their loved ones during this critical period (Colello, 2007; PDQ Supportive and Palliative Care Editorial Board, 2022). These state-level policies collectively contribute to the support and assistance of informal caregivers in their crucial role during end-of-life care.

Giunta (2010) conducted a comprehensive study that applied the communications model to analyze the multifaceted factors influencing the statewide implementation of the National Family Caregiver Support Program (NFCSP). This research revealed that demographics, historical context, and organizational structures were pivotal in shaping service delivery within individual states. Multivariate analysis demonstrated that the conceptual model effectively explained the provision of Caregiver Support Group Training (CSGT) as a distinct service, with historical context significantly influencing its delivery. These findings hold significant implications for caregiver support policies, particularly in end-of-life care, highlighting the importance of tailored programs that address informal caregivers' emotional and instructional needs, ultimately positively impacting their grieving process (Giunta, 2010).

Similarly, Mezey and colleagues (1997) directed their attention toward the Patient Self-Determination Act (PSDA), a federal law in the United States that sets guidelines for end-of-life care. The study highlighted the importance of understanding how ethics, networks, professional organizations, and nursing homes can receive support in addressing challenges during the implementation of the PSDA. This research is significant for our current study because it highlighted the importance of having more specific guidelines, better training programs, and increased compliance with the PSDA. These factors are crucial in ensuring that patients and their informal caregivers receive care centered around their needs during end-of-life situations.

In addition, the study conducted by Weiner and Tilly (2003) centered on policy matters and the implementation of integrated care model programs in the United States,

explicitly addressing end-of-life care. It has been revealed that policymakers at both the federal and state levels are starting to acknowledge the significance of Medicare and Medicaid as crucial funding sources for medical and long-term care in end-of-life scenarios. On the other hand, Weiner and Tilly (2003) also found that patients often run out of hospice benefits before they receive all the necessary end-of-life care. The information provided is essential for the ongoing research because it helps us understand informal caregivers' financial difficulties within the limited time frame of policy changes and funding options.

Policymakers must prioritize initiatives focusing on providing fair and equal care for informal caregivers, particularly during the crucial stage of end-of-life care. To summarize, this section looked closely at the federal and state policies regarding end-of-life care and examined how these policies have affected informal caregivers. The text highlights the need for reform and increased health policy and administration accountability, pointing out current policies' ambiguous nature and potential shortcomings. Federal policies such as the Family and Medical Leave Act (FMLA) and the Older Americans Act (OAA) aim to support caregivers. However, it is essential to note that there are still gaps in these policies, which will be further discussed in the upcoming section. The policies of different states vary when it comes to offering services like respite care and home-based support. Giunta's study emphasizes the significance of previous experience in successfully implementing caregiver support programs. The research conducted by Mezey et al. highlights the importance of having more specific guidelines and better adherence to federal laws, such as the PSDA, to provide care that

frankly focuses on the needs of residents. According to the study conducted by Weiner and Tilly, it sheds light on the difficulties caregivers encounter when securing funding for end-of-life care. In general, the analysis emphasizes the importance of assisting informal caregivers during this crucial stage of life.

### **Navigating Long-Term Care Challenges for Informal Caregivers**

Goodhead and MacDonald (2007) noted that it was in the late 1970s when the Social Development Council in New Zealand first began defining families with special caregiving responsibilities. The term *informal caregiver* has undergone various changes in meaning, reflecting the complexities of this role. According to their definition, these families are the ones who go above and beyond in aiding and paying attention to vulnerable individuals in their households, such as individuals who are older or have physical disabilities (Goodhead & MacDonald, 2007). In this initial understanding, it was observed that society tends to overlook these families and their caregiving efforts while also highlighting the emotional reasons that drive them to provide care (Goodhead et al., 2007). In their later work, Goodhead and McDonald (2007) further clarified the term by emphasizing that an informal caregiver assists individuals unable to carry out tasks independently due to their age or stage of development. In 1992, Charlton shed light on the concept of opportunity costs in caregiving, portraying caregivers as individuals whose lives are constrained by their responsibilities (Goodhead & MacDonald, 2007).

In the United States, Levine and Murray (2004) offered a more comprehensive viewpoint, stating that an informal caregiver refers to any individual who offers or organizes unpaid or paid assistance for someone dealing with an illness or disability (p.

18). The definition has been expanded to encompass not only household chores but also medical requirements, thus broadening the range of caregiving responsibilities. In their study, Savage and Bailey highlighted the continuous and unpaid aspect of caregiving. They specifically focused on the everyday assistance provided to individuals who cannot carry out daily activities (Savage & Bailey, 2004, p. 111). According to Collings (2006), there is a distinction between formal and informal caregiving. The author emphasizes that informal caregiving occurs within an emotional setting, involves a broader array of duties, and is frequently unforeseen and unrecognized economically (Collings, 2006).

The various definitions provide context to better understand informal caregiving as a role that involves deep emotional dedication, voluntary involvement, and significant responsibilities. The changing demographics and evolving policy frameworks significantly impact the ever-changing landscape of long-term care and the individuals who provide informal caregiving in the United States. One crucial aspect to consider here is how the American family structure has changed, specifically looking at the Baby Boomer generation and their decision to have fewer children (Wettstein & Zulkarnain, 2019). The research conducted by Wettstein and Zulkarnain (2019) highlights the importance of adult children as primary caregivers for their elderly parents. However, this suggests that there will soon be a greater need for Long-term Services and Supports (LTSS). The findings they discovered have significant implications, especially when considering the decreased support from family for older individuals who have difficulties with everyday tasks (Wettstein & Zulkarnain, 2019).

Additionally, the growing demand for healthcare and daily support among the

elderly has led to the development of specialized residential and care facilities (Caroline et al., 2019). However, these facilities have often prioritized catering to higher income brackets regarding commercial interests, resulting in a significant portion of middle-income seniors being overlooked (Caroline et al., 2019). The fact that a considerable number of middle-income seniors may lack the necessary resources and ability to access specialized care is a matter that demands attention from both public policymakers and the private sector (Caroline et al., 2019).

The upcoming issue of insufficient financial resources for specialized long-term care among middle-income seniors highlights the need for policies to address the demand and availability of informal and formal caregiving, (Caroline et al., 2019). The comparison of these studies brings to light an important point: Informal caregivers are burdened with more responsibilities, while formal care options are becoming increasingly unaffordable, leading to a crisis in long-term care for older adults. As the number of children available to care for their aging parents decreases, there is a growing need for long-term services and support (LTSS) (Wettstein & Zulkarnain, 2019). This demand is made even more urgent by the expected increase in seniors who require assistance with mobility and healthcare but cannot afford specialized care facilities (Caroline et al., 2019).

These challenges make for a complicated situation where informal caregivers may feel intensified grief and guilt, calling for public policy and education interventions considering the emotional and social aspects involved. The increasing need for Long-term Services and Supports (LTSS) because of changes in the population (Wettstein &

Zulkarnain, 2019) and the high cost of specialized care for middle-income seniors (Caroline et al., 2019) have essential effects on end-of-life care education and public policy. Due to the limited number of informal caregivers, it is crucial to prioritize educational programs that can equip these caregivers with the necessary skills to navigate the challenges of end-of-life care. This will help alleviate their feelings of grief and guilt. At the same time, public policy must tackle the financial obstacles preventing individuals with lower incomes from accessing high-quality end-of-life care. These challenges emphasize the importance of education and public policy in enhancing the quality of end-of-life care and alleviating informal caregivers' emotional and social challenges.

### **End-of-Life Care Health Policies in the United States, Canada, and Germany**

End-of-life care represents a critical but challenging component of the healthcare system, and the universal healthcare frameworks in Canada and Germany provide an intriguing lens through which to explore the policy disparities that influence this aspect of care. Although both nations feature universal healthcare systems, the approaches and regulations concerning end-of-life care manifest in diverse ways; it sheds light on these policy distinctions, exploring their potential impacts on the quality of care and caregivers' experiences.

Fowler and Hammer (2013) discussed how the Canadian healthcare model highlights a significant conflict between the medical practices within the system and the end-of-life choices of the aging population in Canada. While it is commendable that this nation is committed to providing healthcare for all, there seems to be a tendency to prioritize hospital-based interventions and rely heavily on aggressive medical treatments.



Numerous elderly Canadians prefer a comfort-centered palliative approach, thereby highlighting a potential misalignment between this practice and their expressed end-of-life preferences (Fowler and Hammer (2013) as the population ages and the need for end-of-life care services grows, it becomes more and more apparent that policies must be adjusted accordingly. Morrison (2018) takes this further by exploring the details of practical policy measures. According to Morrison (2018), focusing on three main factors is important. First, there should be an active involvement with influential policymakers to shape the development of strategies. Second, there should be a consistent practice of quality audits to maintain high standards of care. Furthermore, finally, there should be a significant allocation of financial resources from the government, specifically for palliative care.

A focus on patient-centric approaches characterizes the German policy landscape. On the other hand, the German healthcare system is known for its patient-centered approach, which is made possible by its decentralized and insurance-based structure (Kluge, 2018). In Germany, policy measures go beyond just providing hospital-based solutions. They actively strive to integrate palliative care units and home-based services into the options for end-of-life care. According to Radbruch and Payne (2009), these options aim to personalize the healthcare experience for each patient, providing a more comprehensive range of choices and ensuring greater comfort. Germany's policy commitment is commendable due to its robust funding mechanisms for research in palliative care. This helps promote best practices and encourages a thoughtful, evidence-based approach to developing policies and delivering healthcare.

The Canadian and German models provide valuable lessons on how policy structures impact end-of-life care. However, they also reveal different approaches to involving stakeholders, allocating funding, and ensuring quality control (Fowler & Hammer, 2013; Kluge, 2018; Morrison, 2018; Radbruch & Payne, 2009). While Canada should reconsider and realign its policy approach (Fowler & Hammer, 2013; Morrison, 2018), Germany provides valuable insights on incorporating a patient-centric focus within a decentralized system (Kluge, 2018; Radbruch & Payne, 2009). Regarding end-of-life care, Canada and Germany have different policy frameworks that impact how care is provided and experienced by different stakeholders.

In Canada, the funding for end-of-life care is mainly incorporated into the overall healthcare budget. This approach restricts the availability of specialized interventions (Fowler & Hammer, 2013). On the other hand, Germany takes a different approach by providing specific funding for palliative care, which allows for more personalized and detailed interventions for patients (Radbruch & Payne, 2009). Regarding stakeholder engagement, Canadian policy recommendations emphasize the importance of including senior policymakers from the beginning, which shows a top-down approach (Fowler & Hammer, 2013; Morrison, 2018). Contradictorily, Germany takes a different approach by implementing a multi-stakeholder engagement model that involves healthcare providers and patient advocacy groups. This approach helps to make policies more relevant and responsive (Kluge, 2018).

Regarding quality assurance, while Canada tends to rely on a centralized audit system, as mentioned by Morrison in 2018, Germany's healthcare structure is

decentralized, which means that quality control is carried out at a more localized level. This allows for better accommodating patient-specific needs, as highlighted by Kluge in 2018. Lastly, when it comes to the impact on caregivers, it is worth noting that Canada's existing policies create a mismatch between the preferences of patients and the way healthcare is provided, which ultimately adds to the stress experienced by informal caregivers (Fowler & Hammer, 2013). In Germany, though, policies tend to be more in tune with what patients want, which could help ease caregivers' emotional and psychological strain (Radbruch & Payne, 2009).

### **U.S. Health Policy on End-of-Life Care with Canadian and German Landscapes**

Various federal and state policies in the United States provide an intricate support network for end-of-life care and informal caregiving. According to the U.S. Department of Labor (2023), the FMLA grants eligible caregivers the opportunity to take unpaid leave, acknowledging their need for time off without directly addressing their financial challenges. The U.S. Department of Labor (2023) illustrates that the primary objective of the Older Americans Act (OAA) and its National Family Caregiver Support Program (NFCSP) is to allocate resources specifically to address the needs of older individuals and their caregivers. This focus contrasts with the broader aim of Canada's universal healthcare model. However, ambiguous policy guidelines can lead to inconsistent implementation, a concern similarly raised in critiques of the Canadian healthcare system (Fowler & Hammer, 2013). The Medicare and Medicaid programs in the United States, similar to Germany's specialized palliative care funding, offer specific services for end-of-life care. However, it is essential to note that these services have time limitations and

may not cover the entirety of a patient's care, as mentioned by Weiner and Tilly (2003) and the U.S. Department of Health and Human Services (2023). Germany's dedication to palliative care research and targeted interventions starkly contrasts this limitation (Kluge, 2018; Radbruch & Payne, 2009).

In the United States, state-level policies address end-of-life care. These policies, such as Medicaid waivers and Advance Directive laws, aim to provide a comprehensive approach like Germany's decentralized healthcare system. This approach allows for localized quality control and patient-centered care options (Kluge, 2018). However, the effectiveness of these initiatives at the state level depends on different factors, such as demographic and historical circumstances.

Giunta's (2010) research on the National Family Caregiver Support Program (NFCSP) sheds light on these aspects. The effectiveness of this intricate landscape reflects the complex challenges faced by healthcare policy in Canada. According to Morrison (2018), engaging with policymakers early on and conducting thorough quality audits are crucial. At the same time, Mezey et al. (1997) emphasize the importance of the United States improving the Patient Self-Determination Act (PSDA) guidelines to enhance end-of-life care; these policies align with the Canadian perspective, emphasizing the need for precise policy development and implementation (Morrison, 2018).

To sum it up, the current U.S. policies offered some support for end-of-life care and informal caregiving. However, there was a clear need for reforms that address issues like unclear guidelines, inadequate financial assistance, and limited duration of services. To address these limitations, we can consider and integrate aspects from both the

healthcare systems in Canada and Germany. For instance, Canada emphasizes the importance of aligning with patient preferences (Fowler & Hammer, 2013), while Germany adopts a patient-centric and research-oriented approach (Kluge, 2018; Radbruch & Payne, 2009). By addressing these gaps, healthcare policies in the United States could better cater to informal caregivers' requirements- ultimately influencing their grief and guilt experiences while providing end-of-life care.

### **Gaps in the Literature: The Need for Policy Solutions and Public Education**

The literature revealed significant gaps that prompted reflection on the importance of policy solutions and comprehensive public education regarding end-of-life care for informal caregivers. The review highlighted the lack of research on the emotional stress experienced by informal caregivers when they have to make and live with end-of-life decisions, using the information provided in educational materials. Furthermore, it is worth noting that despite the efforts of palliative care experts to promote policy measures and public awareness, there seemed to be a lack of research on the importance of providing end-of-life education to informal caregivers. The lack of research in this area highlighted the need for policy interventions that prioritize the emotional well-being of informal caregivers, helping to create a fairer and more supportive environment for end-of-life care.

Knowledge and understanding are deficient surrounding end-of-life care and palliative care, preventing patients and their families from receiving the best care and support. Numerous studies have brought attention to these gaps and stressed the importance of policy solutions and education in tackling the challenges identified herein.

A recent study by Hidalgo-Andrade and Mascialino (2022) emphasized that there is a significant amount of misinformation surrounding the use of morphine in palliative care, including healthcare professionals. The study emphasized the importance of education policies and interventions in enhancing health literacy and influencing how patients and caregivers perceive end-of-life care and using opioids in palliative care.

Clarke and Seymour (2010) highlighted the significance of promoting understanding and support for end-of-life care; education is a crucial factor in helping informal caregivers deal with the challenges associated with grief, highlighting the need for policy development that considers caregivers' specific circumstances and needs.

Clarke and Seymour (2010) further emphasized the need for community-based approaches and education to address informal caregivers and family members' challenges, such as confusion and lack of adequate support. Similarly, Breen and O'Connor (2007) delved into the realm of grief experiences and put forth a range of solutions that encompassed enhanced education, research tailored to specific contexts, and evaluation of interventions. Their research highlighted the challenges in implementing grief support and intervention changes while emphasizing the importance of collaboration among various stakeholders, such as researchers, practitioners, policymakers, and caregivers.

The current body of research strongly suggests that education is a crucial catalyst for translating theoretical insights into real-world applications, especially when improving end-of-life care at the community level. Ho et al. (2020) build upon this concept, positing that focused educational initiatives can clarify misconceptions related to

the use of morphine, which in turn could alleviate patient discomfort and suffering. In a similar study, Garcia (2018) highlighted the underutilization of hospice and palliative care services while emphasizing the necessity of offering communication guidance and community education within local hospice agencies. These scholarly contributions highlight that well-designed educational programs can enhance the quality of care and break down unfounded beliefs that may impede effective pain management.

In research carried out by Lebaron et al. (2014), they explored the obstacles that hinder effective pain management and limited access to opioids for individuals with cancer; they emphasized the significance of implementing policy changes and enhancing education to enhance pain management strategies for these patients. In their study, Skantharajah et al. (2022) emphasized the importance of providing further education to practitioners and clinicians. This education would help them gain a deeper understanding of the complex experience of grief among informal caregivers. Stein and Fineberg (2013) examined the differences in advance care planning policies between the United States and the United Kingdom, emphasizing the importance of providing culturally sensitive education and involving patients and communities to enhance participation and adherence to planning documents.

In their recent study, Vargas-Escobar et al. (2022) employed social mapping techniques to pinpoint obstacles to accessing palliative care. They underscored the significance of education in tackling these challenges and enhancing care delivery. The studies highlight the importance of teamwork among researchers, policymakers, practitioners, and caregivers. They emphasized the need to work together to create well-

rounded approaches prioritizing education and community engagement. By doing so, we can improve end-of-life care and provide better support for patients and their families.

The current literature gaps showed a clear need for policy solutions and widespread public education on end-of-life care for informal caregivers; it is especially important when addressing the emotional stress they experience while making and living with end-of-life decisions. Even though palliative care experts have been advocating for policy solutions and education, it was clear that there is a lack of literature on end-of-life education for informal caregivers. This gap highlighted the need for policy interventions prioritizing their emotional well-being, and it is important to address this issue promptly. Researchers, policymakers, practitioners, and caregivers must work together and develop strategies sensitive to individuals' specific needs at the end of their lives; collaboration is crucial in improving the quality of care and support provided.

### **Conclusion**

Chapter 2 comprehensively explored the effect of policy on informal caregivers' experience of grief with end-of-life care. The analysis revealed the complex interplay between public policy, informal caregivers' emotional well-being, and the intricacies of end-of-life care. By critically examining the literature, I uncovered gaps in current knowledge, identified limitations in existing policies, and established the rationale for the proposed study. The research problem at the core of this study is the lack of comprehensive understanding regarding how public policy addresses informal caregivers' perceptions of end-of-life care and its impact on the death and dying process. Existing federal and state guidelines are often vague, leading to suboptimal implementation and a



dearth of clear educational resources for informal caregivers. The relevance of this problem lies in the emotional stress and complex decision-making processes faced by informal caregivers, emphasizing the need for effective policy interventions. The literature review underscored the importance of addressing the emotional well-being of informal caregivers, recognizing grief as a significant mental health issue, and highlighting the value of tailored care during this taxing period.

Moreover, the review revealed research gaps, calling for policy solutions and comprehensive public education on end-of-life care for informal caregivers. The proposed study aims to fill this void by utilizing a qualitative approach and incorporating Simon's Bounded Rationality Theory and evidence-based policymaking to propose reforms prioritizing end-of-life education, equity, and mental health services. By contributing novel insights and guiding policy change, the study sought to enhance support for informal caregivers and foster a more compassionate end-of-life care environment. Ultimately, this literature review serves as the foundation for the proposed study, emphasizing the importance of informed policy interventions that prioritize the emotional well-being of informal caregivers, thereby improving end-of-life care and promoting a more compassionate and equitable caregiving environment.

### Chapter 3: Research Method

The purpose of this general qualitative study was to understand informal caregivers' perceptions of how policy on end-of-life care impacts the death and dying process and how education influences their experience of grief and guilt. The study explored the challenges and cognitive limitations of informal caregivers who have provided end-of-life care using a qualitative approach. By incorporating evidence-based policymaking and Simon's bounded rationality theory, the research provided insights into how specific policy provisions can effectively support informal caregivers during this emotionally demanding time. The results of this study may be used in implementing policy changes that focus on educating about end-of-life matters, ensuring fairness, and enhancing mental health support for informal caregivers to reduce unnecessary emotional distress while improving the quality of caregiving. Ultimately, this study aimed to provide new perspectives that can help shape policy, improve the assistance given to informal caregivers, and create a more caring environment for end-of-life care.

This chapter aligns the research plan with my dissertation's focus on caregivers' grief and guilt experiences in end-of-life care. My research plan centered on the impact of education on the grief and guilt experiences of informal caregivers in end-of-life care situations. In this chapter, I revisit the core research question from Chapter 1, which emphasizes the central concept of education's effect on caregivers' guilt and grief. This chapter also addresses my role as a researcher, personal or professional relationships with participants, and strategies for managing biases and ethical concerns, including IRB approvals and informed consent procedures. Methodologically, I specify

the population under consideration, justify sampling strategies, and outline participant selection criteria. I explain the details of my recruitment and data collection procedures and detailed any potential challenges. My data analysis plan ensures a clear connection between data and the research question while emphasizing trustworthiness through expert peer review, journaling, and member checks, all within an ethical framework safeguarding participant privacy and data integrity.

### **Research Design and Rationale**

In my research, the central concept I delved into was the effect of policy on informal caregivers' experience of grief and guilt with end-of-life care. This concept encompassed the impact of various policies, regulations, and guidelines surrounding end-of-life care on the emotional and psychological responses of informal caregivers who support individuals nearing the end of their lives. These caregivers, often family members or friends, navigate grief as they witness the impending loss of their loved ones. End-of-life care involves providing comfort, dignity, and quality of life to individuals in the final stages of their lives due to terminal illness or age-related factors. I aimed to shed light on the intricate relationship between policy, education, and the grief experience of informal caregivers, contributing valuable insights for scholars and policymakers in the field.

One research question guided this study that directed the focus toward understanding the grief and guilt experiences of informal caregivers in the context of end-of-life care: What do the grief and guilt experiences of informal caregivers reveal that would guide policy change for education on end-of-life care? By addressing this question, the study uncovered insights that could potentially influence policy changes

related to education on end-of-life care. This could improve support systems for informal caregivers and enhance the quality of end-of-life care provided to patients.

In my research, I chose a general qualitative approach that draws from various disciplinary traditions, including empirical, healthcare, social science, policy analysis, and qualitative research (Tavallaei & Talib, 2010). This approach was essential for comprehensively understanding the multifaceted issue of the effect of policy on informal caregivers' experience of grief within the context of end-of-life care. The dynamics of informal caregiving within end-of-life care were influenced by myriad factors, such as healthcare systems, social networks, family dynamics, financial considerations, social determinants, and policy frameworks, highlighting the relevance of an interdisciplinary perspective.

By integrating policy analysis into my research methodology, I examined the implications of policies on informal caregivers, thus contributing valuable insights to evidence-based policymaking (Tavallaei & Talib, 2010). Furthermore, by embracing the qualitative research tradition, I maintained a human-centered approach, ensuring that the nuanced lived experiences of caregivers were captured and understood. This synthesis of perspectives allowed me to tap into rich and diverse data sources, thereby enhancing the depth and extent of my study's findings and recommendations.

### **Role of the Researcher**

The researcher is the primary instrument in qualitative research, making it important to conduct ethical evaluations to assess biases and assumptions for ensuring the effectiveness of the study (Ravitch & Carl, 2021, p. 1). In the capacity of an observer and

researcher, I recognized the role I played in investigating the impact of policy on informal caregivers' experiences of grief within the context of end-of-life care. As a nursing home administrator, my role is connected to my research topic, which centers on the impact of policy on informal caregivers' experiences of grief in the context of end-of-life care. This alignment between my profession and research allowed me to gain unique insights and firsthand knowledge regarding the dynamics in this critical aspect of healthcare and caregiver support. Leveraging my diverse professional credentials, including my certification as a dementia practitioner and nationally certified end-of-life care practitioner, I was equipped with the knowledge and empathy necessary to engage effectively with participants in my research.

While engaging in research that is closely related to my professional role as a nursing home administrator does carry the potential for bias, being mindful of these considerations and taking deliberate steps to minimize bias helped ensure that I conducted research that was both academically rigorous and informed by my professional experience as a nursing home administrator. In my dual role as a nursing home administrator and researcher, it was crucial to address potential bias (Mehra, 2002; Poggenpoel & Myburgh, 2003). Bias demands rigorous management, defined as any predisposition obstructing impartial inquiry (Pannucci & Wilkins, 2010).

To mitigate bias, I maintained an open-minded stance to explore unexplored planes within the studied population, adopting a holistic approach to inquiries (Mehra, 2002). My data collection method, which comprised a researcher-created online survey questionnaire through Survey Monkey, was thoughtfully designed to guarantee the

selection of participants devoid of prior affiliations with my organization's family members or staff, thereby reducing potential biases and conflicts of interest. Drawing upon my expertise in quality assurance and performance improvement, I employed intuitive analysis techniques and journaling to mitigate biases. Journaling (Meloy, 1994) and interpersonal-process recall ([IPR], Kagan, 1980) allow researchers to delve into thoughts and impressions that arise during interviews. In journaling, I documented my thoughts before and after conducting interviews in handwritten notes in a physical notebook and recorded audio notes, enabling me to uncover thoughts, feelings, and impressions that may have otherwise remained obscure or unrecognized the study (Kagan, 1980; Meloy, 1994).

### **Methodology**

In my research, I employed a basic qualitative study to understand informal caregivers' perceptions of how policy on end-of-life care impacts the death and dying process and how education influences their experience of grief and guilt by integrating EBPM and Simon's bounded rationality theory. The methodology details used for this study entailed a thorough outline of various aspects, including participant selection and the instruments used. This approach gave me a nuanced understanding of the subject matter and allowed for a rich and in-depth data analysis (Mbuagbaw et al., 2020). Furthermore, I employed strategies for participant recruitment, data collection, and data analysis that were designed to ensure the reliability and validity of my findings, contributing to the robustness of my study's outcomes.

## **Participant Sampling**

The population comprised of informal caregivers involved in end-of-life care in the United States. The inclusion criteria for participants of this study were (a) direct experience with informal caregiving at end-of-life care and (b) having experienced the loss of a loved one within the past 36 months but not sooner than 3 months. The exclusion criteria for this study were (a) participants who have experienced a partnership between my nursing home organization and a partnering hospice provider and (b) participants who had a healthcare background or experience.

To recruit participants, I used the LinkedIn network and Facebook. On each of these platforms, I distributed an email invitation (Appendix A) that contained a link to Survey Monkey, a web-based survey platform. To ensure that participants met the study criteria, I used the skip logic feature to create a custom path through a survey based on each respondent's answers. With question-and-answer piping, I inserted answer text from a question into another question on a later page in the survey. At any point in the survey where a participant met the exclusion criteria, they were directed to the exit page and thanked for their time and interest. This participant selection process ensured the data collected were relevant and insightful for my research.

## **Sample Size**

My goal was to recruit up to 25 informal caregivers and/or family members through an online survey generated through SurveyMonkey. In qualitative research, it is common practice to utilize relatively limited sample sizes, even though there is no unanimous consensus on what constitutes an appropriate sample size (Patton, 2015;

Ravitch & Carl, 2016). Research by Milton et al. (2017) highlighted the importance of practical sample considerations, such as participants' willingness to provide rich data, particularly in emotionally charged contexts. Thus, using SurveyMonkey's anonymous interface addressed this challenge by fostering candid responses from participants who may be hesitant to disclose such information through traditional methods like telephone interviewing (Milton et al., 2017); this approach ensured a larger sample size, enhancing the richness and depth of qualitative data collected.

In qualitative research, assessing the adequacy of purposive samples is frequently guided by the concept of saturation (Morse, 1995, 2015; Sandelowski, 1995). Saturation, initially conceptualized as *theoretical saturation* by Glaser and Strauss in 1967 (Glaser & Strauss, 2017), forms an integral component of their influential grounded theory methodology in qualitative research. It refers to the point in the research process when no new information or themes emerge from the data, indicating that the sample size is sufficient for the research objectives (Given, 2008). I adhered to the saturation principle, continuing data collection until all significant issues or insights had been thoroughly explored and no new themes emerged, ensuring a comprehensive exploration of my research question (Bryant & Charmaz, 2007, p. 611). By recruiting up to 25 informal caregivers and family members, I continued data collection until saturation was achieved, ensuring a comprehensive understanding of their lived experiences of guilt and grief in the context of end-of-life care and education.

### **Researcher-Developed Instrumentation**

For my planned research design, I used Survey Monkey to create and distribute



open-ended questions to collect data and feedback from my respondents. This survey allowed me to ask open-ended questions that explore the lived experiences and perceptions of end-of-life care for informal caregivers. The survey protocol I employed facilitated the collection of data through a sequence of interconnected questions with the primary goal of obtaining valuable information to address emerging research inquiries (Creswell, 2018) related to the informal caregiver's experience of education or support during the caregiving timeframe and after their loved ones passing. The questions were developed based on the key concepts presented in the literature review in Chapter 2 and the theoretical framework. This section presents each of the major sections and question topics, along with the justification for inclusion.

### ***Survey Introduction***

In a research study, inclusion and exclusion criteria screening questions were crucial for ensuring that the study's participants met certain specific requirements. These criteria help select the most appropriate participants for the research, ensuring the results are accurate and meaningful (Capili, 2021). Inclusion criteria were used to determine who could participate in the study, while exclusion criteria were used to identify individuals who should not be included. By clearly defining these criteria, researchers can better control variables that could affect the study's outcomes; this helps ensure the research findings' reliability and validity (Dekkers et al., 2022). Screening questions assisted in recruiting the most appropriate participant to understand informal caregivers' perceptions of how policy on end-of-life care impacts the death and dying process and how education influences their experience of grief and guilt by integrating evidence-based policymaking

and Simon's bounded rationality theory (see Appendix C). Inclusion criteria included providing care for someone at end-of-life and having experienced a loss of a loved one within the past 36 months. Exclusion criteria included having clinical healthcare experience and a partnership with the Grand Healthcare System in Pawling, New York, or received hospice service through the Grand Healthcare System in Pawling, New York.

The participant's demographic questions were important because they helped the researcher understand the characteristics of the participants involved in the study. This information can include but is not limited to age, gender, education level, income, ethnicity, and other relevant demographic data (Call et al., 2023). Understanding the demographics of the participants can provide valuable context for interpreting the study results and ensuring that the findings apply to the intended population. It also allows for identifying any potential biases in the sample and helps generalize the results to the larger population. Additionally, demographic data can be used for subgroup analysis, revealing important differences in how certain groups respond to the studied variables (Burton, 2021). Collecting demographic information is crucial for ensuring the validity and applicability of research findings. Table 1 depicts the demographic questions that were used to provide valuable context for interpreting the data.

**Table 1***Participant Demographic Questions*

<p>1. What is your age?"</p> <p>A. 0 - 17 years old</p> <p>B. 18 - 30 years old</p> <p>C. 30 - 45 years old</p>	<p>5. Length of Time as an Informal Caregiver: Please enter the length of time you have been an informal caregiver in years or months.</p> <p>1 – 3 years</p> <p>4 – 6 years</p> <p>7 – 10 years</p> <p>More than 10 years</p>
<p>2. What gender do you identify as?"</p> <p>A. Male</p> <p>B. Female</p> <p>C. _____ (Short Answer Space)</p> <p>D. Prefer not to say</p>	<p>6. What is your annual household income?"</p> <p>A. Less than \$25,000</p> <p>B. \$25,000 - \$50,000</p> <p>C. \$50,000 - \$100,000</p> <p>D. \$100,000 - \$200,000</p> <p>E. More than \$200,000</p> <p>F. Prefer not to say</p>
<p>3. Relationship to the Care Recipient: Please select your relationship to the care recipient from the following options:</p> <p>A. Spouse,</p> <p>B. Child,</p> <p>C. Sibling,</p> <p>D. Friend,</p> <p>E. Other</p> <p>F. Prefer not to say</p>	<p>7. Please specify your ethnicity."</p> <p>A. Caucasian</p> <p>B. African-American</p> <p>C. Latino or Hispanic</p> <p>D. Asian</p> <p>E. Native American</p> <p>F. Native Hawaiian or Pacific Islander</p> <p>G. Two or More</p> <p>H. Other/Unknown</p> <p>I. Prefer not to say</p>
<p>4. What is the highest degree or level of education you have completed?"</p> <p>A. Some High School</p> <p>B. High School</p> <p>C. Bachelor's Degree</p> <p>D. Master's Degree</p> <p>E. Ph.D. or higher</p> <p>F. Trade School</p> <p>G. Prefer not to say</p>	

Each participant was screened based on the inclusion and exclusion criteria and their response to the age demographic question about the participant's age. If participants were under the age of 18, they were atomically excluded from the study. If participants were excluded, they received a thank-you message and were informed that they did not meet the specific participant requirements for this research study. The participants who chose to complete the survey clicked on the SurveyMonkey link and were directed to a welcome page that included a thank-you message, a brief overview of the research purpose, and a survey outline. Those who proceeded were invited to continue and prompted to sign the informed consent form. Those who select the "I consent" button can complete the remainder of the survey; those who did not provide consent were redirected to a thank-you message.

### *Survey Questions*

#### **Getting to Know You.** Questions included

- Question a): Reflecting on your journey of informal caregiving, please share a little about the person you provided care for and what relationship you shared.
- Question b): In a few sentences, tell me a little about yourself and some of the moments that stand out to you most during your time as an informal caregiver.

#### **Valuable Support and Resources.** The prompt was

Managing the emotional stress of caring for a loved one during end-of-life care can be stressful, and many people benefit from various resources such as support groups, online chats, the internet, respite services, educational services, and even

access to hospice organizations.

Questions included

- Reflecting on your time caring for your loved one, please describe any support or resources you used and which made the biggest difference for you.
- Tell me when you felt you were missing support or resources and how these would have made things easier.

These questions were inspired by evidence-based policymaking principles (Hasani, 2019), this question probes the real-world impact of policies and programs on caregivers. It aligned with the literature's call for policy solutions that address emotional and practical support needs (Clarke & Seymour, 2010; Garcia, 2018). The aim was to identify effective support and underutilized hospice and palliative care service gaps, contributing to developing policies responsive to caregivers' diverse needs.

Seeking Help or Information. The prompt was "Finding help or accessing information about how to physically and emotionally care for someone nearing the end of their life can be challenging." The question was "Please describe your experience of accessing the information you needed and how this impacted your caregiving experience." This question was rooted in bounded rationality (Simon, 1972), recognizing caregivers' limitations in accessing and processing information. It sought to explore the efficacy and accessibility of educational resources, directly addressing the literature gap concerning the need for clear, comprehensive end-of-life care education (Breen & O'Connor, 2007; Hidalgo-Andrade & Mascialino, 2022). Insights from caregivers' responses highlight how current policies and educational strategies meet or fail to meet

their informational needs, informing evidence-based policy improvements.

**Ways of Dealing with Difficult Times.** The prompt was

Caring for someone at the end of their life can be hard. People have different ways of dealing with these tough times. Some folks might go for a walk, talk to friends or family, pray, or sometimes have a drink.

Questions included

- Question a): What are some things you've done to help yourself cope with the emotional challenges of caregiving for someone at end-of-life?
- Question b): Thinking of the difficult decisions you had to make regarding pain management and end-of-life comfort, tell me about what strategies you used to cope with the guilt or grief associated with those decisions.

These questions were informed by the gaps identified in the existing literature concerning the coping mechanisms of informal caregivers during the provision of end-of-life care. It focused on understanding the various strategies these caregivers might employ to handle grief or guilt. The significance of comprehending the psychological well-being of informal caregivers and the potential for misinformation regarding pain management strategies was highlighted by researchers like Hidalgo-Andrade and Mascialino (2022). These insights suggest an essential need for comprehensive support addressing informal caregivers' informational and emotional needs. Moreover, Breen and O'Connor (2007) emphasize the complexity of providing grief support, advocating for solutions from community-based education to assessing interventions.

The literature revealed a notable gap in our understanding of the personal coping

strategies of informal caregivers, particularly in terms of substance use, like alcohol, or engagement in spiritual or religious practices for emotional support (Clarke & Seymour, 2010; Garcia, 2018). Additionally, Skantharajah et al. (2022) underscore the importance of educating healthcare providers on the intricacies of grief and bereavement, highlighting how informal caregivers navigate these emotionally taxing experiences personally and within community frameworks. By inviting informal caregivers to share the methods they've found effective for managing the emotional challenges of their role, this question aimed to bridge a critical gap in the literature. It sought to provide insights into the myriad ways informal caregivers cope with the emotional demands of their responsibilities. The collected data was instrumental in developing targeted support interventions and systems that acknowledge the full spectrum of coping strategies used by informal caregivers, from health-promoting activities to potentially risky behaviors. Gaining such insights is crucial for formulating policies and educational programs that robustly support the well-being and resilience of informal caregivers (Stein & Fineberg, 2013; Vargas-Escobar et al., 2022).

**Reflections on Decision-Making and Support Received.** The prompt was Feeling overwhelmed or uncertain about the best course of action is a common experience, particularly when under pressure to make quick decisions. Reflecting on the support or advice you received during such times, consider both the helpful and unhelpful guidance. As you look back on the decisions made regarding comfort measures, pain management, last wishes, and the final moments of your loved one's life, assess your feelings toward those choices.

### Questions included

- Question a): In a few sentences, tell me how that support or advice affected your decision-making.
- Question b): In a few sentences tell me about how these tough decisions affected your grief or guilt process.

These questions were informed by Simon's Bounded Rationality Theory, which explores the impact of cognitive constraints on caregivers' decision-making (Schaathun, 2022). It sought to uncover how policy and educational support influence caregiving decisions and the emotional aftermath of those decisions. The feedback can illuminate areas where policies may better facilitate informed, confident decision-making among caregivers, aligning with the literature's emphasis on informed consent and decision support (Mezey et al., 1997).

**Influence on Thoughts and Feelings.** This question was "Reflecting on your experience of providing end-of-life care, can you tell me about how this experience has shaped your thoughts and feelings about life and dealing with challenging situations?" This question delved into the emotional and psychological terrain of caregiving, echoing the literature's focus on the profound emotional stress caregivers endure (Stroebe et al., 2014; Martz & Morse, 2016). It reflected on the theoretical perspective of bounded rationality by examining how caregiving experiences reshape caregivers' perceptions and decision-making processes. The insights gained can guide the creation of supportive educational and policy interventions that acknowledge and address the emotional complexities of caregiving.



**Experiences with Pain Management or Comfort Care.** This question was “If you had experiences deciding on pain management or comfort care options for your loved one’s comfort, how did you make those decisions, and what information sources guided you?” This question focused on the decision-making process regarding pain management or comfort care, reflecting Simon’s Bounded Rationality Theory’s emphasis on cognitive constraints in decision-making (Schaathun, 2022). It broadened the scope to include various pain management strategies, not just morphine, addressing the need for clear, accessible information and guidance in making these decisions (Hidalgo-Andrade & Mascialino, 2022). Responses illuminated the informational needs of caregivers and the factors influencing their decisions, highlighting areas for educational and policy improvements in providing evidence-based, compassionate care options.

**Emotional Impact of Pain Management Decisions.** The prompt was “Decisions about pain management and comfort care can evoke emotions of guilt for some and peace of mind for others, particularly when there are so many stigmas about end-of-life care and pain management.” Questions included

- Question a): Reflecting on your perceptions of end-of-life care, how did any decisions regarding pain management or comfort care affect you emotionally?
- Question b): Please describe any concerns or feelings of guilt associated with those decisions and how you coped with those feelings.

By exploring the emotional impact of decisions related to pain management or comfort care, this question delved into the psychological experiences of informal caregivers, aligning with the literature on caregivers’ emotional stress and guilt (Martz &

Morse, 2016; Stroebe et al., 2014). It acknowledged the emotional complexities of end-of-life care decisions, informed by bounded rationality in the face of emotionally charged decisions (Schaathun, 2022). The insights gained inform the development of supportive resources and policies that address not only the informational but also the emotional needs of informal caregivers, facilitating a more holistic approach to end-of-life care planning and support.

**Final Question.** The final question was

Reflecting on your journey as a caregiver during end-of-life care, considering the support you received, the decisions you made, and the emotional impact it had on you, tell me how you envision carrying forward the lessons learned and experiences gained from this caregiving experience in your life moving forward.

### ***Survey Completion***

After completing the survey or choosing to withdraw from participation, participants underwent debriefing procedures. Participants received a thank you for their contributions and a clear explanation of the research's purpose. I reaffirmed my commitment to protecting anonymity and confidentiality and provided information on any follow-up procedures or opportunities to access research findings.

### ***Content Validity***

Content validity is crucial in developing assessment instruments, especially in the social and health sciences domains. Almanasreh et al. (2019) outlined a detailed framework for assessing content validity that includes three key stages: development, judgment, quantification, and subsequent revision and reconstruction. They argued that

this rigorous evaluation process is essential, particularly when instruments are used to measure health outcomes or to influence clinical decisions, emphasizing the need for content that is both relevant and representative of the targeted construct (Almanasreh et al., 2019).

Similarly, Sireci (1998) highlighted the importance of content validity within the scope of construct validity, noting that it is a crucial initial step in developing and evaluating instruments. Sireci discusses the risks associated with diminishing the role of content validity, such as the potential to overlook essential elements that demonstrate the instrument's representativeness and relevance to the measured constructs. He advocates ensuring content representation in instrument development to avoid these pitfalls (Sireci, 1998). I utilized the works of Almanasreh et al. (2019) and Sireci (1998) to emphasize the foundational role of content validity, merging my methodological thoroughness with theoretical insights to highlight its critical importance in my effective research instrument development.

When evaluating the perspectives of Almanasreh et al. (2019) and Sireci (1998), it became evident that content validity played a pivotal role in instrument development and evaluation across various fields. Both emphasized the importance of ensuring content representation, highlighting the need for rigorous assessment processes to enhance the quality of assessment instruments. To bolster the content validity of my study, I engaged in an expert validation process involving nurse practitioners and medical doctors who possess expertise in end-of-life care and the grief process. These professionals were asked to evaluate the suitability of my participant survey for the intended population.

They assessed whether the questions adequately capture the nuances of health policy's impact on the grief and guilt experienced by informal caregivers (Almanasreh et al., 2019). I asked them to provide feedback on whether my participant survey is appropriate for the target population and whether the questions are sufficient to understand the impacts of health policy on the informal caregiver's experience of grief and guilt, and I incorporated their feedback into the survey questions.

### **Procedures for Recruitment, Participation, and Data Collection**

Upon approval from the Walden Institutional Review Board (IRB), I posted the invitation flier (see Appendix A) on my LinkedIn page and Facebook, and the Walden University participant pool process. Survey responses occurred daily over multiple weeks which ensured comprehensive coverage and a robust dataset. Throughout this process, I continued to prioritize the rights and well-being of our participants, upholding ethical standards in research and striving for meaningful insights that can contribute to understanding end-of-life care and informal caregivers' experiences.

The first step in participating in the research survey was to volunteer by accessing the provided link or scanning the QR code on the informational flier. Once participants entered the survey, they encountered a screening questionnaire to determine if they met the eligibility criteria (see Appendix C). This ensured that the data collected aligned with the study's parameters. Participants were then greeted with a welcome letter to set the groundwork for the research study. This letter highlighted the call for volunteers to participate in a study on informal caregiving at end-of-life care. It outlined the criteria for volunteers and explained the purpose of the study, which is to understand the

perspectives and experiences of caregivers to improve support and resources for people providing care to loved ones at the end of life. The letter also detailed the procedures involved in participating, including completing an online survey and reviewing a transcript of the interview (see Appendix B). Those who volunteered to participate in the study and met the inclusion criteria (see Appendix C) then proceeded to the Informed Consent page, where they could review the study details and consent to participate.

The survey experience was tailored for each participant based on their responses using SurveyMonkey's skip logic feature. Participants encountered custom survey paths relevant to their circumstances and perspectives. Additionally, question-and-answer piping enhanced the survey's depth by allowing information from one question to inform subsequent questions, providing a more nuanced understanding of participants' experiences and perceptions. For participants who did not meet the screening criteria or chose not to provide consent, they were directed to an exit page and received a heartfelt thank you for considering participation, along with an explanation of their ineligibility to continue with the study (see Appendix D). Upon consent, participants completed a demographics questionnaire, proceeding directly to the main questionnaire. Gathering demographic information allowed a better understanding of the sample composition and identify any potential biases in the data. Throughout the survey process, I prioritized data security and confidentiality. My equipment and software, including an iPhone for survey monitoring and a laptop with Office 365 for data storage and analysis, are encrypted and securely housed in a password-protected home office.

After completing the survey or choosing to withdraw from participation,

participants underwent debriefing procedures. The debriefing procedures provided participants with additional information after they participated in the study. This involved reiterating the study's objectives. Debriefing allowed participants to understand the purpose of the study assisted in mitigating any potential psychological or emotional impact of their participation. Participants were also provided with an opportunity to ask questions and seek further clarification about the research. This was done following the Ethical Guidelines of Walden University to ensure that participants were fully informed about the study they were involved in.

Participants received a sincere thank you for their contributions and a clear explanation of the research's purpose (see Appendix F). I reaffirmed my commitment to protecting anonymity and confidentiality and provided information on any follow-up procedures or opportunities to access research findings. Participants were encouraged to reach out with any questions or concerns, emphasizing their participation's voluntary and confidential nature.

### **Data Analysis Plan**

My data was analyzed as the survey responses were obtained, utilizing NVivo14 for comprehensive analysis. I employed NVivo14, a qualitative data analysis software tool Saldaña (2018) recommended. This software enabled me to implement descriptive and process coding methods, extracting codes from the data to facilitate thematic analysis and the identification of relevant word and phrase codes.

In my research, I used pre-coding, predetermined, or deductive coding to analyze survey transcripts, as Smith (2015) and Saldaña (2015) outlined. I chose pre-coding for

its systematic approach to data analysis, ensuring consistency and rigor throughout the process. By applying predetermined codes to the survey transcripts, I maintained a focused analysis aligned with the research objectives. Additionally, pre-coding allowed for integrating the theoretical framework guiding the study, enabling a deeper exploration of theoretical concepts within the survey data.

Pre-code selection was informed by my research questions, theoretical framework, and relevant literature, identifying key concepts or themes related to the study objectives and translating them into coding categories. These codes included themes like guilt, morphine for comfort, absence of discussions regarding side effects, hastened or quickened death, emotional distress, limited cognitive function due to stress, caregiving responsibilities, both supportive and non-supportive interactions, and frustration stemming from perceived lack of support. My study employed evidence-based policymaking and Simon's bounded rationality theory that explored how certain policy provisions could support informal caregivers during emotionally challenging times.

To expand on the discussion of data analysis procedures in the context of thematic analysis (TA), as discussed by Braun and Clarke (2021), I followed a structured, rigorous approach that built upon their established method:

1. Familiarization with Data: I began by immersing myself in the raw data to gain a comprehensive understanding of its depth and breadth, reading through all materials extensively, and making initial notes where patterns emerge.
2. Generating Initial Codes: I systematically coded the data in a manner that pertains to the research question, segmenting the data into meaningful

elements that serve as the building blocks for the thematic framework, using software like NVivo.

3. **Searching for Themes:** I collated codes into potential themes, gathering all data relevant to each potential theme and creating visual representations like mind maps to see how codes interconnect and form overarching themes.
4. **Reviewing Themes:** I checked if the themes work with the coded extracts and the entire data set, using tables or diagrams to test the validity of each theme.
5. **Defining and Naming Themes:** I developed a detailed analysis of each theme, determining the essence of each theme and what aspect of the data each theme captures, creating detailed theme descriptions with supporting data extracts.
6. **Summarizing/Writing the Report:** I weaved together the analytic narrative and data extracts, contextualizing the analysis within the relevant literature and using rich examples from the data to illustrate the report's claims.

In my approach to enhancing the rigor of the thematic analysis process, I actively integrated theoretical frameworks to guide the interpretation of my data, drawing on the recommendations of Braun and Clarke (2021). This involved a deep and continuous engagement with the data, where I constantly questioned my analyses and interpretations to ensure a comprehensive understanding, as suggested by Saldaña (2018). Using deductive coding I aligned the analysis systematically with my theoretical and research aims (Smith, 2015). Lastly, I used the practice of peer review and collaborative analysis, as discussed by Morse (2015), which allowed me to receive feedback from my committee members in providing fresh insights, challenging existing interpretations, and refining



themes, thus significantly enhancing the analytical credibility of my study. To enhance the rigor of the thematic analysis process, I integrated my theoretical frameworks to align with my research and to guide my interpretation of the data, continuously questioning my analyses and interpretations, and enhancing the analytical credibility.

### **Issues of Trustworthiness**

Trustworthiness is a crucial aspect of qualitative research, reflecting confidence in the study's methods, interpretation, and data quality (Lincoln & Guba, 1985). Lincoln and Guba's (1985) criteria for ensuring trustworthiness, namely transferability, credibility, confirmability, and dependability, are widely used in qualitative research (Merriam & Grenier, 2018). The following section discusses the strategies I employed to address these criteria.

#### **Credibility**

Credibility, in the research context, refers to the assurance of reliability achieved through techniques such as sustained involvement, observation, peer review, analysis of negative cases, and thorough member validation (Morse, 2015). To enhance credibility, I used a comprehensive approach to maintain my research integrity, encompassing the entire process from the initial literature review through data collection and analysis to ensure credibility, specifically utilizing the techniques of expert validation, reflexivity, and saturation.

Content validity was established by seeking input from colleagues within the healthcare field, including Hospice nurse practitioners and physicians. I collaborated with these professionals to review my survey questions and ensure their alignment with the

experiences of informal caregivers, specifically focusing on the aspects of education and support during end-of-life care and the subsequent 12 months following the passing of a loved one. Content validation through expert judgment, as defined by Fernández-Gómez et al. (2020), involves seeking informed opinions from individuals with a proven track record in the relevant field, recognized by their peers as qualified experts capable of offering valuable insights, evidence, judgments, and assessments. The evaluation process through expert judgment entails inviting individuals to provide their assessments or opinions regarding a particular instrument or aspect (Guillot-Valdés et al., 2022).

I will incorporate reflexivity throughout the entire research process. Early in my dissertation, I incorporated weekly audio journals that will be transcribed into a Word document for reference and reflection. Ortlipp (2008) emphasized that a reflective journal serves the purpose of methodically analyzing one's perspective in qualitative research. This involved carefully examining my objectives and underlying assumptions while remaining attuned to subjectivities and belief systems that helped maintain credibility.

### **Transferability**

Initially, I believed that conducting in-person interviews with my research participants would be the optimal approach for this study. However, given my background as a healthcare nursing home administrator with expertise in providing comfort and support to grieving individuals, particularly informal caregivers in the context of nursing homes, I recognized that my unique perspective might influence the participants differently than someone without my background. Although conducting in-person interviews could provide more in-depth insights, the primary objective of my

study was to assess the impact of healthcare policy on how informal caregivers utilize educational support during end-of-life care, as well as its influence on their experiences of grief and guilt. Considering these factors and aiming for greater transferability of the research findings, I decided to employ an online survey. This approach allowed for a broader range of participants and facilitated a more inclusive and diverse representation of my study, ultimately enhancing its transferability to different contexts and populations.

The technique of employing an online survey for participant selection introduces a form of convenience sampling, which involves selecting participants who are readily accessible and willing to participate (Whitehead et al., 2020, p. 118); this approach potentially reaches a broader spectrum of individuals from various demographics, geographical locations, and cultural backgrounds, thereby enhancing the transferability of research findings to different contexts and populations.

Online surveys allow for a more inclusive and diverse representation of the study's target population, promoting greater external validity and generalizability of the results (Miner et al., 2012). Furthermore, thick description, a qualitative research technique that provides rich and detailed descriptions of the research context and participants' experiences, can further enhance the transferability of findings by offering a nuanced understanding of the phenomena under investigation (Ponterotto, 2006). Utilizing a thick description approach enabled me to delve deeply into the intricacies and complexities of my survey participants' perspectives. This method facilitated a comprehensive understanding of the informal caregiver's viewpoints, making it easier to apply the research findings to end-of-life care situations.

## **Dependability**

The process of ensuring dependability and confirmability was intricately woven into every facet of participant selection, survey protocols, and procedures in my study. I anticipated no alterations to the survey questions throughout the online survey period, as they underwent thorough validation to ensure alignment with the research focus and withstand expert scrutiny (Krosnick & Presser, 2010, p. 303). Utilizing the SurveyMonkey platform, data collection adhered to a uniform format to maintain consistency and enable future replication. Questions were presented in a consistent order, ensuring that each participant received the same set of questions and an equal opportunity to respond. The significance of question order and consistency was highlighted by their potential influence on participants' responses, particularly when questions were related (Krosnick & Presser, 2010). This approach ensured consistency across surveys while enabling adaptability to uncover unexpected insights and informal caregiver experiences.

In studies guided by theoretical frameworks such as phenomenology, grounded theory, feminism, and ethnography, maintaining a close connection between researchers and the survey text is essential for both the research design and the philosophical underpinnings of the methodology (Halcomb & Davidson, 2006). Therefore, preserving an exact record of the survey proved invaluable in facilitating data analysis by bridging the gap between researchers and their participant's data; maintaining a verbatim account of the survey proves highly advantageous as it aids in data analysis by fostering a closer connection between my research and the participant's attestation to the accuracy of the survey results, they submit. Hence, after the survey, all participants had the chance to

review their responses for accuracy. This extra measure of dependability not only facilitated future research duplication on various topics but also contributed to a dependable understanding of the impact of health policy on the grief and guilt experienced by informal caregivers; it underscored the importance of educational support and policy refinement to bridge gaps and foster social change.

### **Confirmability**

Introspective reflexivity in research, as defined, underscores the importance of self-awareness and introspection within the research journey. It calls upon researchers to be cognizant of their biases, beliefs, and preconceptions that may subtly influence the entire research process, from data collection to its subsequent interpretation (Patnaik, 2023). I remained attuned to the factors that could influence my study's confirmability, especially when designing the online survey questionnaire. Factors such as age, gender, cultural backgrounds, and various diversities were under constant consideration. For instance, my ethnicity was a significant variable that warranted attention, as it could pose a barrier during the interview process, potentially inhibiting participants from opening up and sharing their vulnerabilities. Being aware and proactive about my positionality enhanced the integrity of my research process and its ultimate outcomes.

### **Ethical Concerns and Procedures**

To access participants' data for this research study, a systematic approach guided by the Institutional Review Board (IRB) consent form was implemented. My professional networks leveraged initial recruitment, with invitations disseminated through LinkedIn and the Walden participant pool, directing potential participants to the survey link.

Furthermore, hospice organizations were engaged in recruitment through online invitations, as the researcher emailed the study invitation to these organizations, requesting that they forward it to eligible personnel and social media.

The consent procedure was initiated on the first page of the online survey, hosted on Survey Monkey, which served as the consent form. Participants indicated their willingness to participate by clicking the “I consent and continue” button. The entire data collection process was conducted online, which streamlined the research process and upheld ethical standards in participant recruitment and consent. This comprehensive approach ensured the integrity of the data and compliance while increasing the success of research replication. The consent form outlined that the researcher sought to involve up to 25 participants. It also provided a clear description of any reasonably foreseeable risks or discomforts, highlighting that the minimal risks are comparable to those encountered in daily life. Additionally, any substantial (although not anticipated) risks were thoroughly explained in the consent form, and support services were provided through a hyperlink on the survey if the participants felt they needed assistance. It is explicitly mentioned that there were no direct benefits for volunteers, as the primary aim of the study is to contribute to society and bring about social change. There was no monetary compensation offered for participating in the study.

In Chapter 4, I took measures to ensure that demographic information, such as gender, ethnicity, education, and age, which may be included in the results, was presented in a manner that protects the identities of the volunteers. To maintain confidentiality, I opted for an anonymous data collection method, even going so far as to ensure that I, as

the researcher, would not have access to information regarding volunteer participation.

When sharing data with future collaborators, I will take steps to remove all identifiers to safeguard participant confidentiality. Robust data security measures are implemented, with data stored exclusively on devices under my control. For coding purposes, I maintained a separate list of codes and identifiers. Additionally, I took precautions against device theft, including setting up password protection and regularly updating software and security measures. To ensure genuine anonymity, I disabled IP address tracking and selected settings that prevent any tracking or follow-ups.

Additionally, I provided information about Walden University's Research Participant Advocate. It explicitly stated that I serve as a nursing home administrator, and this role is entirely distinct from the study in question. Furthermore, participants were informed that their data would be retained for 5 years and subsequently disposed of by deleting all files stored on either a hard drive or a laptop device. These comprehensive measures underscored my commitment to upholding the highest ethical standards throughout my research journey.

### **Summary**

In this chapter, I outlined the detailed methodology for my study, which focused on understanding how education impacts the grief and guilt experiences of informal caregivers in the context of end-of-life care. The primary research question was: What do the grief and guilt experiences of informal caregivers reveal that would guide policy change for education on end-of-life care? As both a nursing home administrator and researcher, I am acutely aware of the potential for bias, and I've taken steps to minimize

it, including selecting participants with no prior affiliations with my organization. Employing a purposive sampling strategy, the aim was to recruit approximately 25 informal caregivers, with data collection continuing until data saturation is reached.

For data collection, I've opted for the use of Survey Monkey, an online survey platform, to gather participants' narratives and experiences. Content validity has been ensured through expert validation of survey questions. The data analysis plan involved Saldaña's coding methods and thematic analysis, which will help categorize and interpret participants' experiences. To maintain trustworthiness, I adhered to principles of credibility, transferability, dependability, and confirmability.

Ethical considerations were paramount in my research. Informed consent was obtained at the beginning of the online survey, and participants' confidentiality and data security were rigorously safeguarded. My commitment to conducting this study with integrity and adherence to ethical standards remains unwavering, as I aim to contribute valuable insights into the experiences of informal caregivers in end-of-life care and the potential impact of policy changes in this domain.

Next, Chapter 4 examines the data collection process, the conduct of in-depth analysis, and synthesizes results within the context of this study on the impact of education on informal caregivers' experiences of grief in end-of-life care. Through a scholarly lens, this chapter explains how the gathered data contribute to addressing the research problem and objectives, providing empirical evidence essential for understanding the nuanced dynamics of informal caregiving during the end-of-life journey.



#### Chapter 4: Results

In this chapter, I examine the analysis and results of my study on how education and policy affect the experiences of informal caregivers dealing with grief in end-of-life care. My research was designed to understand how these policies impact caregivers' emotional journeys and how education can support them. Specifically, I aimed to answer the question: "What do informal caregivers' grief and guilt experiences reveal that would guide policy change for education on end-of-life care?" In this chapter, I begin by describing any significant personal or organizational factors that may have influenced participants during the study, such as workplace connections or personal affiliations. Next, I provide a detailed look at the participants' demographics to give context to the findings and then outline the data collection process, including the number of participants, where and how often data was collected, and any deviations from the planned methods. In the Data Analysis section, I describe the approach to thematic analysis (TA) outlined by Braun and Clarke (2021). I also discuss how I ensured the trustworthiness of my findings, including credibility, transferability, dependability, and confirmability.

Next, the Results section addresses the research question by presenting data and supporting quotes and including summary tables that illustrate the frequency, deductive coding, and analysis of the data. This analysis led to the identification of emerging patterns, which were subsequently introduced and coded. I explored the experiences of these caregivers and identified four important themes that have significant implications for policy and support systems. I then explain how these themes represent the various

challenges faced by the informal caregivers in this study, especially regarding accessing support and resources, the cognitive challenges impacting their decision-making, and the deep emotional impact of their responsibilities. Finally, a synthesis of the themes is provided, correlating them with my research question. This structured approach of the chapter provides a clear and comprehensive view of how policies and education influence the emotional experiences of informal caregivers in end-of-life care, offering insights that could inform future policy and support systems.

### **Setting**

There were no known personal or organizational conditions that influenced participants or their experience at the time of the study that may influence the interpretation of the study results. The study was conducted through an online survey, providing a stable and consistent environment for all participants and ensuring that external factors did not affect their responses. This approach allowed for the collection of unbiased and reliable data reflecting the true experiences and perceptions of the informal caregivers involved in the research.

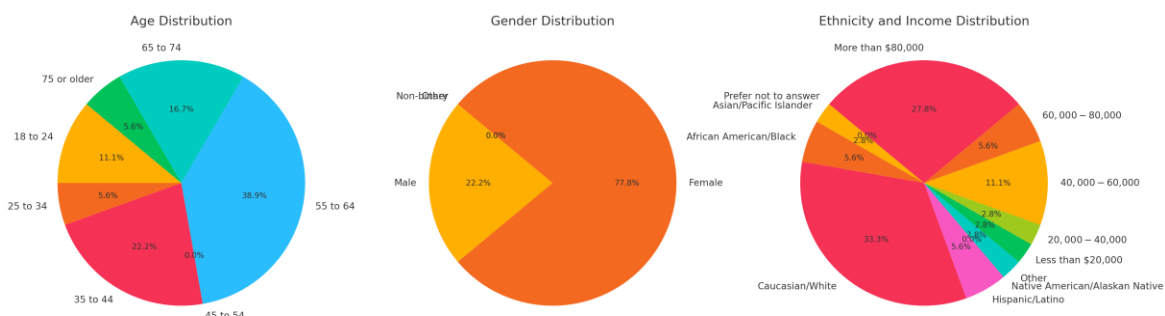
### **Demographics**

The demographic data from the survey reveals that most respondents are aged between 55 and 64 (38.9%; see Figure 2). The gender distribution shows a predominant female representation at 77.8%. Ethnicity data reveals a primarily Caucasian/White demographic at 66.7%, followed by African American/Black and Hispanic/Latino each at 11.1%. Income levels vary, with a notable 55.6% of respondents earning more than \$80,000 annually. These points collectively highlight the diverse age, gender, and

socioeconomic backgrounds of the informal caregivers surveyed, emphasizing the prominence of older, female, Caucasian individuals with relatively high income levels in this caregiving population as seen in Figure 2.

**Figure 2**

*Basic Demographic Information of Survey Respondents*



**Data Collection**

There were no significant variations in the data collection process from the initial plan presented in Chapter 3, and the survey was successfully administered online. No unusual circumstances were encountered, and the high completion rate of informed consent and near-complete survey participation indicated a well-executed data collection process. This comprehensive approach ensured that the survey results were robust and reflective of the experiences of the informal caregivers who participated, providing valuable insights for the study.

Although 25 respondents completed the informed consent section, only 18 of the 25 respondents continued to provide demographic and survey data on their experiences with end-of-life care, including caregiving and the loss of a loved one within the past 36 months. The survey was conducted online using SurveyMonkey, initially launched on

June 27, 2024, and responses slowed between June 30, 2024, and July 2, 2024, which was expected because of the July 4 long weekend. The survey was relaunched on LinkedIn and Facebook on July 5, 2024, which yielded better results, likely due to respondents returning to work. After saturation was reached, the survey closed on July 10, 2024.

The survey summary of completion, dated July 1, 2024, showed incomplete data for seven of the 25 respondents. Although the seven respondents confirmed they provided care for someone at the end of life and consented to participate in the survey, they did not progress to completion, so their data were not used. The potential reasons for the incomplete responses could include time constraints, emotional strain, the length or complexity of the survey, technical issues, perceived lack of immediate benefit, and privacy concerns. Additionally, the average time spent on incomplete surveys was 4.2 minutes, suggesting that distractions or other priorities may have led participants to leave the survey idle and incomplete.

Data collection was a one-time survey conducted within this specified period, with responses recorded electronically and securely stored in the platform's database. The data was then exported to PDF files labeled with survey questions and summary answers, securely stored on my laptop in my home office, and password protected.

### **Data Analysis**

I adhered to the structured and rigorous approach to thematic analysis as outlined by Braun and Clarke (2021). First, to familiarize myself with the data and identify patterns, I progressed from initial responses to broader themes derived from my

theoretical and conceptual framework. I identified codes, categories, and emerging themes based on their frequency and highlighted key points using participants' quotes.

Then, I combined similar responses and questions to formulate the following themes:

- Challenges with accessing and timeliness of support resources
- Psychological impact and enduring guilt
- Information and decision-making constraints
- Hastening Death? Morphine-related guilt

Next, multiple charts were used to visually display the data to illustrate how the codes were interconnected and formed overarching themes. This structured approach helped me envision a comprehensive and rigorous data analysis, allowing for the identification of broader themes and the application of my conceptual framework and theoretical foundation to interpret the results.

Discrepant cases, or outliers, were carefully examined to understand their unique context and why they differed from the majority. For instance, while most respondents reported feeling inadequately supported, a few mentioned having sufficient support and resources. However, they contradicted themselves by stating that while it was adequate, it was still insufficient support. These discrepancies were important as they highlighted the variability in caregiver experiences. These cases were factored into the analysis by acknowledging the diverse range of experiences among caregivers. By incorporating these outliers, the analysis could address the common challenges and contrast the conditions under which caregivers felt adequately supported. This comprehensive approach ensured a balanced understanding of caregiving and underscored the need for

tailored interventions that consider the varying levels of support different caregivers receive.

### **Evidence of Trustworthiness**

In ensuring the credibility of my study, I implemented several strategies as outlined in Chapter 3. Reflexivity was another crucial strategy, where I maintained audio journals transcribed into Word documents for reference and reflection, critically analyzing my objectives and underlying assumptions to maintain credibility.

For transferability, I provided detailed descriptions of the research context, labeled participants, and procedures. This included comprehensive demographic information of the participants, such as age, gender, relationship to the care recipient, and socioeconomic status. By offering rich descriptions, other researchers can determine the applicability of the findings to similar contexts. I decided to employ an online survey instead of in-person interviews, considering my background as a healthcare nursing home administrator and aiming for a broader range of participants. This approach facilitated a more inclusive and diverse representation of my study, ultimately enhancing its transferability to different contexts and populations.

I followed a systematic approach to data collection and analysis to ensure dependability, as documented in Chapter 3. This included consistently applying thematic analysis and coding processes throughout the study. In collaboration with my committee chair, I employed the practice of peer review and collaborative analysis (see Morse, 2015). For example, we conducted several calls to review the survey progress and responses. During these discussions, we examined my data analysis, evaluated emerging

themes, identified potential biases, and assessed the transferability of the findings. This process involved fracturing the data into smaller, more manageable pieces and applying holistic coding to capture the overall essence of the data. This rigorous, collaborative approach allowed me to refine themes, challenge existing interpretations, and ensure the analytical credibility of my study. Additionally, I maintained a detailed audit trail of all data, coding decisions, and analysis steps to allow for future transferability.

Confirmability was achieved by implementing strategies to minimize researcher bias and ensure objectivity. Reflexive journaling allowed me to document personal reflections and potential biases throughout the research process. The findings were grounded in direct participant quotations, providing clear evidence for the themes and interpretations presented. This transparent and systematic approach ensured that the findings were based on the data rather than preconceptions, enhancing the study's confirmability.

## **Results**

### **Theme 1: Challenges with Accessing and Timeliness of Support Resources**

My data showed that informal caregivers often struggled to find the support and resources to manage their caregiving duties effectively. Even when support systems were available, they could be inadequate or hard to access, increasing caregivers' stress and making it difficult to provide the best care. From analyzing the responses to questions Q17, Q18, and Q19, I identified a prominent theme: the difficulty in accessing clear and reliable information and support. Many caregivers expressed significant challenges in effectively obtaining the necessary information and resources to care for their loved ones

during end-of-life stages. This theme consistently appeared across the responses, highlighting a widespread issue among informal caregivers. Caregivers frequently reported feeling overwhelmed by the complexity of medical jargon and treatment options, often without sufficient guidance from healthcare professionals. This lack of accessible information increased their stress and uncertainty, making it difficult to feel confident in their caregiving abilities. Many respondents relied on the internet or ad-hoc advice from friends and family, sometimes leading to inconsistent or inadequate support.

The absence of professional guidance, combined with the emotional and financial strain of caregiving, left many caregivers feeling isolated and unsupported. This aligns with Simon's theory of bounded rationality, where individuals make decisions based on limited information and within their cognitive constraints. The responses indicate a clear need for more structured, accessible educational resources, professional support, and centralized information to alleviate the burden on caregivers and improve their decision-making processes. This theme underscores the importance of EBPM in addressing these gaps and providing comprehensive support systems for informal caregivers, guiding my holistic coding approach to ensure these critical issues are highlighted and addressed in my analysis. difficulty in accessing clear and reliable information and support.

### ***Question 17***

The first question in this survey asked, "Reflecting on the time you spent caring for your loved one, please describe any support or resources you used and which ones made the biggest difference for you?" In analyzing the experiences of informal caregivers, it is evident that a significant gap in support and resources exists. Notably,



100% of the 18 respondents reported insufficient support or resources during their caregiving journey. Even those who stated they had adequate support found it inadequate, as it was often untimely and arrived too late to impact the critical decisions they had to make leading up to their loved one's death.

Respondent 2 highlighted the struggle to access necessary assistance, stating, "I could have used more help getting the right places - it was hard to figure out where to go for help with things like house equipment and medication stuff." This sentiment is echoed by Respondent 4, who emphasized the need for a broad range of support: "More comprehensive financial assistance, emotional and mental health support, more robust caregiver training, and respite care services." The complexity of navigating the healthcare system was a major challenge for Respondent 11, who remarked, "One of the biggest challenges was understanding the healthcare system. Wished for more specialized help, like counseling or support groups for caregivers." Fifty-two percent of respondents ( $n = 10$ ) identified that they received effective support but could have used more, while 48% ( $n = 8$ ) did not identify effective support at all.

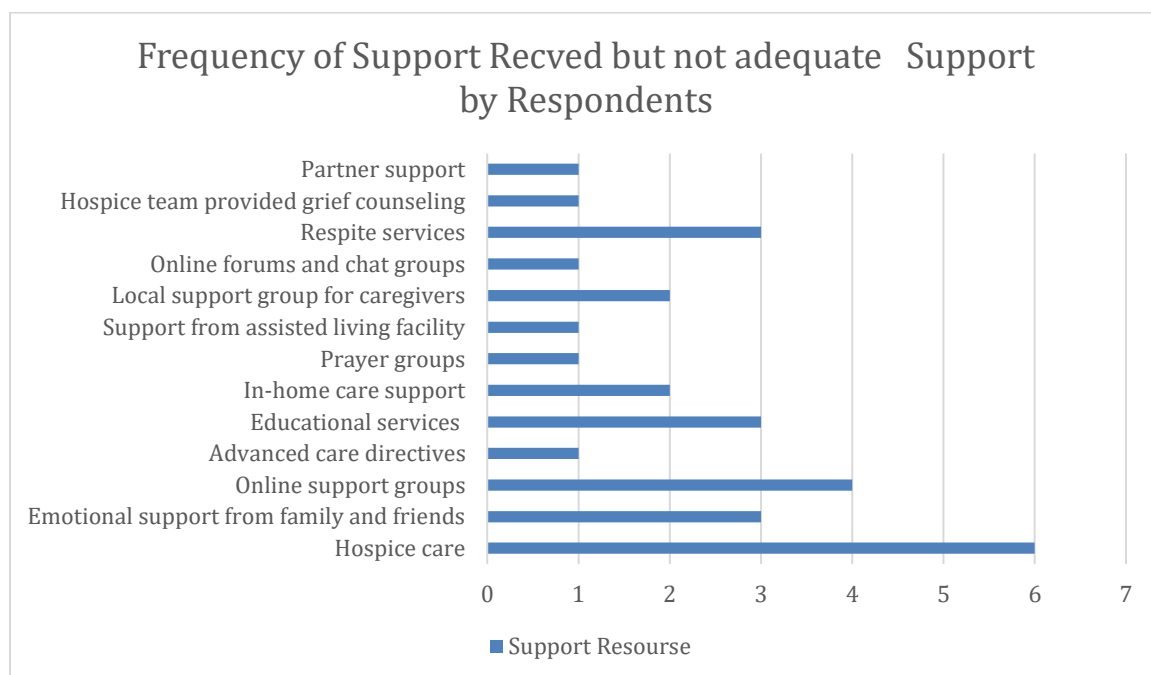
### ***Question 18***

The second question in this survey, labeled Q18, asked: "Tell me about when you felt you were missing support or resources and how these things would have made things easier?" Figure 3 illustrates the frequency with which respondents mentioned various support systems utilized during caregiving, however, they still felt they were missing adequate support despite using the resources they accessed. Categories include partner support, hospice team-provided grief counseling, respite services, online forums and chat

groups, local support groups for caregivers, support from assisted living facilities, prayer groups, in-home care support, educational services, advanced care directives, online support groups, emotional support from family and friends, and hospice care.

### Figure 3

*Frequency of Missing Support by Respondents*



In analyzing the responses to the question, “Tell me about when you felt you were missing support or resources and how these things would have made things easier,” it is evident that all 18 respondents identified significant gaps in the support and resources available to them. This finding highlights the multifaceted challenges informal caregivers face, including emotional, financial, and logistical difficulties.

Respondent 2 expressed frustration navigating available resources, stating, “I could have used more help getting the right places - it was hard to figure out where to go for help with things like house equipment and medication stuff.” Respondent 4

emphasized the need for a wide range of support, including “more comprehensive financial assistance, emotional and mental health support, more robust caregiver training, and respite care services.” The complexity of understanding and navigating the healthcare system was a major challenge for Respondent 11, who remarked, “One of the biggest challenges was understanding the healthcare system. Wished for more specialized help, like counseling or support groups for caregivers.”

Overall, the responses underscore the critical need for enhanced support systems, better resource allocation, and comprehensive training for informal caregivers. The identified needs span from financial assistance and emotional support to navigating healthcare services and obtaining adequate respite care. This comprehensive understanding of caregivers’ experiences can inform future policies and programs to provide more effective and holistic support for informal caregivers.

### ***Question 19***

The third question in this survey, labeled Q19, asked, “Please describe your experience of accessing the information you needed and how this impacted your caregiving experience.” To analyze the responses, the code “Difficulty Understanding Information” reflects respondents’ challenges in comprehending medical or caregiving information, highlighting issues related to processing information. The code “Frustration with Accessing Information” captures respondents’ experiences of difficulty in finding or obtaining the necessary information, emphasizing the limits they face in accessing critical support. I took quotes related to these codes from the participants’ answers to illustrate these challenges. This approach allowed for a structured data analysis, identifying

specific areas where caregivers struggle and need more comprehensive support.

The analysis of Q19 responses revealed the difficulties caregivers face in accessing information and support. Many respondents found the information available to them confusing and difficult to understand, exacerbating their stress and uncertainty. For instance, Respondent 1 shared, “I am old now so the information was hard to understand. Everything happened so fast.” Similarly, Respondent 3 expressed, “Accessing the information I needed as a caregiver was often a frustrating and overwhelming experience.” The frustration with accessing information was a common sentiment. Respondent 6 stated, “I had a hard time finding the right information, which made me feel more stressed and unsure about how to care for my grandma,” and Respondent 8 added, “Accessing information was very difficult. I am computer savvy and tried calling the numbers or going online to register for help.”

Without clear guidance, many caregivers relied on personal networks or informal sources of support. Respondent 5 mentioned, “I used my phone to search the internet for information and group chats,” while Respondent 11 noted, “I primarily relied on my golf buddies for support and advice because I found the healthcare system and its professionals difficult to relate to.” The lack of professional and structured support was a recurring theme, with Respondent 4 highlighting, “The most impactful support came from the Hospice nurses, who provided clear, compassionate advice.” The deficiency in accessible information significantly impacted caregivers’ emotional and physical well-being, as evidenced by Respondent 15, who described the experience as a “nightmare,” and Respondent 16, who stated, “The difficulty in accessing reliable and comprehensive

information impacted my caregiving experience by increasing my stress levels and uncertainty.” The responses underscored the need for comprehensive education, technological support, and policy improvements to better support caregivers, with Respondent 11 calling for “more structured and reliable information” and Respondent 16 emphasizing the need for “access to a legal advisor or a care coordinator who could provide clear and concise information.”

Figure 4 illustrates the frequency of various challenges identified by respondents in accessing information and support needed for caregiving. Categories were coded from respondents’ phrases, including suggestions for policy improvements, technological barriers, cultural and language barriers, the need for comprehensive education, the need for comprehensive information, effective sources of information, the impact of information deficiency, gaps in professional support, reliance on personal networks, frustration with accessing information, and difficulty understanding information.

#### Figure 4

##### *Frequency of Identified Challenges in Accessing Information and Support*

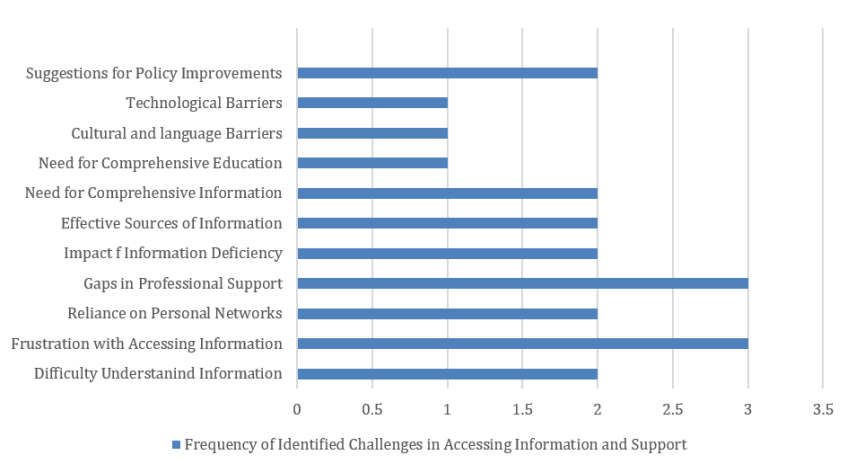
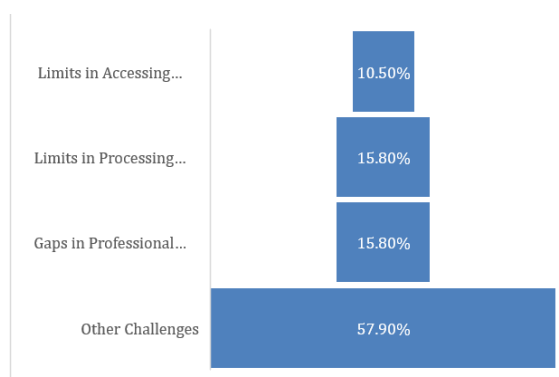


Figure 5 illustrates the percentage of respondents who reported various challenges

in accessing and processing information needed for caregiving. Categories include limits in accessing information, limits in processing information, gaps in professional support, and other challenges.

**Figure 5**

*Limits and Challenges Accessing/Processing Information*



Difficulty Understanding Information reflects the respondents' challenges in comprehending medical or caregiving information. For example, one respondent stated, "I am old now, so the information was hard to understand. Everything happened so fast" (Respondent 1), indicating the processing difficulties some caregivers face due to the complexity of the information provided. Frustration with Accessing Information captures the respondents' experiences of difficulty in finding or obtaining the necessary information. One caregiver mentioned, "Accessing the information I needed as a caregiver was often a frustrating and overwhelming experience" (Respondent 3), highlighting the limits in accessing the information necessary for effective caregiving.

Gaps in Professional Support reflect challenges such as insufficient guidance from healthcare providers, lack of access to trained professionals and respite care, and deficiencies in emotional support. These issues were highlighted by caregivers who

expressed that they felt unsupported in managing their loved one's conditions and their well-being, with one stating, "I did not know how to get the help that we needed until she went to the nursing home" (Respondent 10). The *Other Challenges* segment represents all other challenges reported by the remaining respondents, encompassing gaps in professional support, reliance on personal networks, cultural and language barriers, and technological barriers, among others. This comprehensive view underscores the multifaceted nature of the difficulties faced by informal caregivers and the pressing need for targeted interventions to address these diverse challenges.

### **Theme 2: Psychological Impact and Enduring Guilt**

Caregivers frequently had to make critical decisions under high stress and with limited information. Policies and educational support played a crucial role in shaping how caregivers made decisions and handled their emotional experiences. Effective educational programs and supportive policies helped reduce some of the cognitive burdens by offering clear, accessible information and guidance. The analysis of the data from responses to Q20, Q21, Q22, and Q23 reveals a prominent theme: the significant impact of cognitive constraints and the influence of policy and educational support on caregivers' decision-making and emotional processes. In my data, informal caregivers often faced substantial cognitive challenges, such as feeling overwhelmed, experiencing second-guessing, and dealing with guilt and doubt during critical decision-making moments and the subsequent emotional aftermath. Policy and educational support were crucial in helping caregivers make informed and confident decisions, but this support was often perceived as inadequate or untimely. Caregivers employed various personal coping

strategies, including reliance on social support, engaging in physical activities, spiritual practices, professional counseling, and routine maintenance.

Specific strategies for managing guilt and grief associated with pain management decisions included educational and professional support, spiritual practices, and self-reflection. For instance, Q20 asked caregivers, “What are some things you’ve done to help yourself cope with the emotional challenges of caregiving for someone at end-of-life?” One caregiver noted, “Talking to close friends and family was also crucial as their support and understanding helped me process my feelings and provided much-needed emotional relief” (Q21, Respondent 4). Another respondent stated, “The support and advice I received often came too late, leaving me feeling overwhelmed with guilt and shame about the decisions I had to make regarding my mother’s end-of-life care” (Q22, Respondent 16), while another shared, “These tough decisions profoundly affected my grief and guilt process, intensifying both emotions as I wrestled with the outcomes and consequences of each choice” (Q23, Respondent 3). The emotional impact of caregiving decisions was profound, with caregivers often experiencing intensified feelings of grief, guilt, and isolation.

I applied Simon’s bounded rationality theory, which explores the impact of cognitive constraints on decision-making under limited information and time conditions, and found that it aligns with these findings. My data from Q20, Q21, Q22 & A23 data underscores the need for evidence-based policymaking that provides comprehensive support systems addressing both the informational and emotional needs of informal caregivers. Enhanced policy and educational support, clear and consistent guidance from



healthcare professionals, and targeted interventions can help alleviate cognitive constraints and improve the overall caregiving experience, leading to better outcomes for caregivers and those they care for.

### ***Questions 20 and 21***

The fourth question in this survey section, labeled Q20, asked, “What are some things you’ve done to help yourself cope with the emotional challenges of caring for someone at the end of their life?” The sixth question in this section of the survey, Q21, asked, “Thinking of the difficult decisions you had to make regarding pain management and end-of-life comfort, tell me what strategies you used to cope with the guilt or grief associated with those decisions.

The combined analysis of Q20 and Q21 responses reveals several key personal coping strategies employed by caregivers. Many respondents highlighted the importance of social support, with Respondent 3 noting, “Talking through these decisions with doctors, nurses, and my support group provided reassurance that I was not alone in facing these difficult choices,” while Respondent 4 added, “Talking to close friends and family was also crucial, as their support and understanding helped me process my feelings and provided much-needed emotional relief.” Physical activities were also a common coping mechanism, as illustrated by Respondent 2, who said, “I like to go for a run,” and Respondent 4, who found solace in daily walks: “I found solace in daily walks, which provided me with a brief escape and a chance to clear my mind.”

Spiritual practices were another significant method of coping, with Respondent 15 sharing, “I also prayed a lot, asking for strength and guidance to get through each day,”

and Respondent 9 expressing, “I prayed for forgiveness for not doing everything right.” However, some respondents turned to less healthy coping mechanisms, such as alcohol and medication. Respondent 12 admitted, “I think I drank a lot more than usual, and I took some anti-anxiety medication when things got really tough,” while Respondent 5 said, “I could only get away from the stress when I slept, so I took a lot to help me sleep.” The use of professional counseling was mentioned as beneficial support, with Respondent 7 seeking professional counseling and Respondent 5 utilizing counseling at work. Additionally, maintaining a routine and self-care activities, such as journaling and reflection, were highlighted by several respondents as vital for managing their emotional well-being.

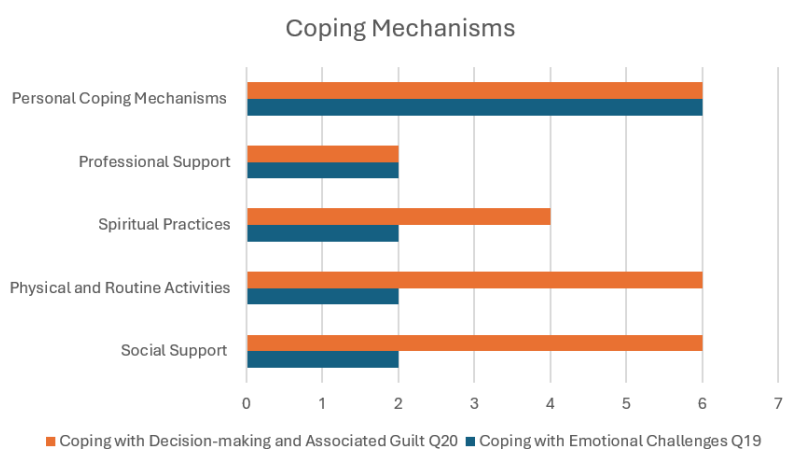
When managing guilt and grief about pain management, respondents emphasized the importance of educational and professional support. Respondent 3 tried to educate themselves about their loved one’s condition, stating, “This knowledge helped me feel more informed and confident in the decisions I had to make,” while Respondent 16 found confidence in seeking guidance from healthcare professionals: “Seeking guidance from healthcare professionals, such as doctors and hospice staff, gave me confidence in the decisions I made.” Spiritual practices, such as prayer, were also significant for some respondents, with Respondent 9 and Respondent 15 both mentioning the role of prayer in seeking forgiveness and strength. Lastly, reflection and self-compassion played crucial roles in managing guilt and grief, as Respondent 3 reflected on shared memories to remind themselves of their care and compassion, and Respondent 4 practiced self-compassion, saying, “I practiced self-compassion, reminding myself that I was doing the

best I could in an incredibly challenging situation.

The clustered bar chart below provides a comparative analysis of the coping strategies employed by caregivers in response to the questions posed in Q20 and Q21. Figure 6 illustrates the number of respondents who reported various coping mechanisms for managing emotional challenges and decision-making stress. It compares responses to two questions: Q19 (coping with emotional challenges) and Q20 (coping with decision-making and associated guilt). Categories include personal coping mechanisms, professional support, spiritual practices, physical and routine activities, and social support.

**Figure 6**

*Coping Mechanisms*



Based on the combined analysis of Q20 and Q21 responses, caregivers employed various personal coping strategies including reliance on social support, engaging in physical activities, spiritual practices, use of alcohol and medication, professional counseling, and routine maintenance. Additionally, when making decisions about pain management for their loved ones, caregivers used educational and professional support,

spiritual practices, and self-reflection to manage the associated guilt and grief. These insights highlight the diverse ways caregivers manage the emotional challenges of caregiving and the specific strategies they use to cope with difficult pain management decisions, emphasizing the need for comprehensive support systems that address their multifaceted needs.

### ***Questions 22 and 23***

The sixth question in this survey, labeled Q22, asked, “In a few sentences, tell me how that support or advice affected your decision-making”. The seventh question in this survey, labeled Q23, asked, “In a few sentences tell me about how these tough decisions affected your grief or guilt process.”

In analyzing the responses to Q22 and Q23, I found significant cognitive constraints that caregivers face when managing guilt and grief. The predefined theoretical framework of Simon’s bounded rationality and evidence-based policymaking set the goalposts for developing a coding scheme for this specific series of questions. I categorized responses that reflected challenges in processing and making decisions under stress and without adequate support. This example demonstrates how deductive coding was systematically applied to categorize and interpret the data by established theoretical concepts. For instance, Respondent 5 mentioned, “I didn’t really have support. I just made choices in real-time.” Respondent 12 shared a poignant reflection, “I wish I would’ve spent more time talking to Mom about what her final wishes were. So much stuff we didn’t know until we were actually going through it and then in the time in the crush in the press is when you become an expert. It was a little bit too late to make a

difference for Mom.” Additionally, the emotional toll of decision-making was evident, as Respondent 3 noted, “These tough decisions profoundly affected my grief and guilt process, intensifying both emotions as I wrestled with the outcomes and consequences of each choice.” These statements highlight the immense pressure and emotional burden caregivers experience due to cognitive constraints and the lack of timely support.

The responses also underscored the influence of policy and educational support on caregivers’ experiences. By applying deductive pre-coding, I identified responses that highlighted the impact of guidance from healthcare professionals and support groups. Many respondents expressed appreciation for the advice provided, which was crucial in their decision-making processes. Respondent 4 emphasized, “The support and advice from the Hospice nurses were instrumental in my decision-making, providing me with the knowledge and confidence to make informed choices about my husband’s pain management and end-of-life comfort.” Similarly, Respondent 14 noted, “During the most overwhelming moments, the support and advice I received significantly impacted my decision-making. Helpful guidance from healthcare professionals and culturally sensitive counselors provided clarity and reassurance.” However, some caregivers felt that more comprehensive support earlier in the caregiving process would have been beneficial, as Respondent 10 shared, “I wish, despite her not being happy in the nursing home, that I would have had that help sooner. They don’t help old people get services very well.” These reflections illustrate the critical role of educational and policy support in alleviating the burden on caregivers.

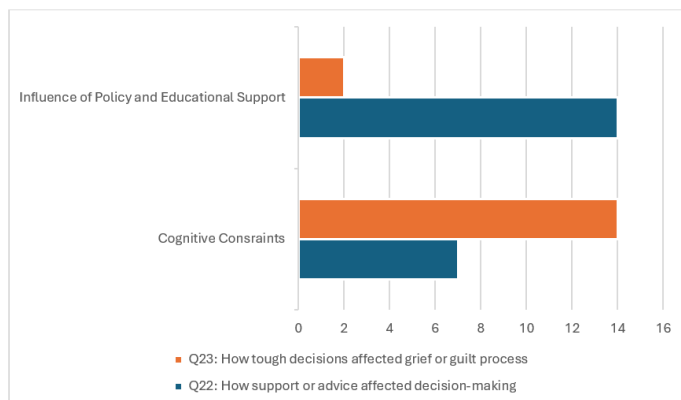
The decision-making process for caregivers also significantly impacts their grief

and guilt. Through deductive coding, I categorized responses that detailed the emotional struggles associated with making end-of-life decisions. Respondent 16 remarked, “The tough decisions I had to make regarding my mother’s end-of-life care significantly intensified my grief and guilt. Each choice, particularly those about pain management and comfort measures, left me second-guessing whether I had done enough or made the right call.” This sentiment was echoed by Respondent 18, who stated, “Even though everyone around me encouraged my decisions and supported them, I still felt/feel guilty and wonder how I could have done things differently. Would she still be here?” The ongoing struggle with guilt and the pressure of making critical end-of-life decisions highlight the need for robust emotional and professional support systems for caregivers. As Respondent 4 explained, “These tough decisions significantly impacted my grief and guilt process. While having the support and advice of Hospice nurses provided some reassurance, the weight of making end-of-life choices for my husband still left me with lingering feelings of guilt and doubt.” This emphasizes the importance of comprehensive support to help caregivers navigate their responsibilities and manage their emotional well-being.

Figure 7 illustrates the number of respondents who reported the influence of policy and educational support and cognitive constraints on their decision-making processes and emotional experiences. It compares responses to two questions: Q22 (how support or advice affected decision-making) and Q23 (how tough decisions affected the grief or guilt process). Categories include the influence of policy and educational support and cognitive constraints.

**Figure 7**

*Impact of Support and Cognitive Constraints on Decision-Making and Emotional Processes*



In response to Q22, Cognitive Constraints were mentioned seven times, and the Influence of Policy and Educational Support was mentioned 11 times. This indicates that caregivers frequently relied on policy and educational support during the decision-making process, highlighting the importance of guidance from healthcare professionals and the impact of educational resources. However, cognitive constraints also posed significant challenges for caregivers as they make decisions without adequate support.

My analysis of responses to Q23 highlights that informal caregivers experience significant emotional and cognitive challenges when reflecting on their decision-making processes, leading to feelings of guilt and second-guessing their choices. The data indicates that “Cognitive Constraints” were mentioned 14 times, whereas “Influence of Policy and Educational Support” was only mentioned twice. This disparity underscores the predominant emotional and cognitive struggles that informal caregivers face. Caregivers frequently reported feeling overwhelmed by the responsibility of making

critical decisions about end-of-life care, describing profound feelings of guilt and self-doubt. For example, one respondent noted, “These tough decisions profoundly affected my grief and guilt process, intensifying both emotions as I wrestled with the outcomes and consequences of each choice. Feeling responsible for my husband’s comfort and well-being added layers of guilt, especially when the outcomes did not align with my hopes or expectations” (Respondent 3). Another caregiver mentioned experiencing a mental breakdown due to the overwhelming stress and emotional turmoil, further entangling their grief with guilt and painful memories: “The pressure and weight of making the right choices for my brother’s comfort culminated in a mental breakdown, where the overwhelming stress and emotional turmoil became too much to bear. This experience profoundly shaped my grief, intertwining it with lingering guilt and the painful memory of those pivotal moments” (Respondent 7).

In contrast, the influence of policy and educational support was scarcely mentioned, suggesting that these factors played a minimal role in alleviating caregivers’ emotional burdens. Another consideration is that informal caregivers don’t give much thought or have knowledge of exactly how policy or education might affect their decision-making. However, one respondent acknowledged the benefit of advanced care directives but still felt the emotional toll of decision-making: “The advanced care directives helped, but the emotional toll of witnessing his suffering and making those final decisions was profound” (Respondent 4).

When I analyzed the data from Q23, the reduced mention of policy and educational support implies that, in hindsight, caregivers felt they had less external



support during critical decision-making moments. The high frequency of cognitive constraints underscores the emotional aftermath of caregiving decisions, with caregivers often experiencing lingering feelings of guilt, doubt, and remorse due to the cognitive challenges they face. This analysis is based on several factors: the significant difference in the frequency of mentions, with cognitive constraints noted 14 times compared to only twice for policy and educational support; the responses that frequently reflected profound feelings of guilt and self-doubt related to decision-making processes; and the few mentions of support mechanisms, suggesting caregivers did not perceive these as significantly alleviating their burden. For example, one respondent said, “These tough decisions profoundly affected my grief and guilt process, intensifying both emotions as I wrestled with the outcomes and consequences of each choice” (Respondent 3). Another described experiencing a mental breakdown due to the overwhelming stress of making decisions for their brother’s comfort: “The pressure and weight of making the right choices for my brother’s comfort culminated in a mental breakdown, where the overwhelming stress and emotional turmoil became too much to bear. This experience profoundly shaped my grief, intertwining it with lingering guilt and the painful memory of those pivotal moments” (Respondent 7). One caregiver acknowledged the benefit of advanced care directives but still felt the emotional toll of decision-making was profound: “The advanced care directives helped, but the emotional toll of witnessing his suffering and making those final decisions was profound” (Respondent 4). Additionally, policy and educational support may not be typical considerations for informal caregivers, which could explain the lower number of respondents mentioning these factors, potentially

skewing their responses. This underscores the need for more effective support mechanisms to help caregivers manage the emotional and cognitive burdens of end-of-life decision-making.

### **Theme 3: Information and Decision-Making Constraints**

The emotional toll of caregiving was immense, especially when it came to making decisions about pain management and end-of-life care. Caregivers often struggled with deep feelings of guilt and emotional distress, wondering if they had made the right choices for their loved ones. This lasting guilt significantly affected their mental health and overall well-being. Using a holistic data analysis approach, I considered the entire context and multiple dimensions of the caregivers' experiences, integrating qualitative data from their reports (Q24, Q25, Q26, Q27, Q28) with theoretical frameworks like Simon's bounded rationality and evidence-based policymaking. The most prominent theme that emerged from analyzing the responses to questions Q24 through Q28 is the profound emotional impact and enduring guilt associated with making decisions about pain management and comfort care. This theme consistently appeared across the responses, highlighting the intense emotional toll that caregivers experience when navigating end-of-life care for their loved ones.

The informal caregivers frequently reported feelings of guilt and anxiety over the decisions they made regarding pain management and comfort care, often questioning whether they had made the right choices and worrying about the potential consequences of those decisions (Q24, Q25, Q26, Q27, Q28). The use of potent medications like morphine, while necessary for alleviating pain, often heightened these feelings of guilt

due to concerns about hastening death or causing harm (Q24, Q25, Q26, Q27, Q28). To cope with these emotions, caregivers relied on a variety of support systems, including healthcare professionals, family members, and support groups. The reassurance and guidance provided by these sources were crucial in helping caregivers manage their guilt and stress (Q24, Q25, Q26, Q27, Q28). Reflecting on the informal caregiving experience, many caregivers emphasized the importance of seeking and accepting support to navigate the emotional challenges of end-of-life care (Q24, Q25, Q26, Q27, Q28). The experience of providing end-of-life care profoundly shaped the informal caregivers' thoughts and feelings about life and dealing with challenging situations. They developed a deeper appreciation for the fragility and preciousness of life, heightened empathy and compassion, and a commitment to advocating for better support systems for future caregivers (Q24, Q25, Q26, Q27, Q28). Despite the emotional toll, informal caregivers demonstrated significant resilience and a desire to use their experiences to help others. Many expressed a commitment to sharing their stories and advocating for improved resources and support networks for caregivers (Q24, Q25, Q26, Q27, Q28).

The profound emotional impact and enduring guilt associated with pain management and comfort care decisions highlight the critical need for comprehensive support systems and reliable information sources for informal caregivers. Addressing these emotional challenges through enhanced support and guidance can significantly improve the informal caregiving experience, enabling them to provide compassionate and informed care while maintaining their well-being. By integrating evidence-based policies that consider the emotional and cognitive constraints described by Simon, caregivers can

be better equipped to manage their responsibilities, reduce feelings of guilt, and enhance their overall well-being. Thus, the intersection of Simon's theory and evidence-based policymaking offers a framework for developing more effective support mechanisms for caregivers.

From analyzing the responses to questions Q24 through Q28, one prominent emerging pattern was the profound emotional impact and enduring guilt associated with making decisions about pain management and comfort care. Many caregivers expressed significant challenges in navigating these decisions, often feeling immense guilt and anxiety over whether they made the right choices for their loved ones (Q26, Q27). The use of potent medications like morphine, while necessary for alleviating pain, frequently heightened these feelings of guilt due to concerns about hastening death or causing harm (Q26, Q27). To cope with these emotions, caregivers relied on various support systems, including healthcare professionals, family members, and support groups. The reassurance and guidance provided by these sources were crucial in managing their guilt and stress (Q26, Q27, Q28). Reflecting on their caregiving experience, many emphasized the importance of seeking and accepting support to navigate the emotional challenges of end-of-life care (Q26, Q27, Q28).

The experience of providing end-of-life care profoundly shaped caregivers' thoughts and feelings about life and dealing with challenging situations. They developed a deeper appreciation for the fragility and preciousness of life, heightened empathy and compassion, and a commitment to advocating for better support systems for future caregivers (Q24, Q25, Q26, Q27, Q28). Despite the emotional toll, caregivers

demonstrated significant resilience and a desire to use their experiences to help others. Many expressed a commitment to sharing their stories and advocating for improved resources and support networks for caregivers (Q24, Q25, Q26, Q27, Q28).

This prominent theme underscores the need for comprehensive support systems and reliable information sources to assist caregivers. Addressing these emotional challenges through better support and guidance can significantly improve the caregiving experience, helping caregivers provide compassionate and informed care while maintaining their own well-being. This aligns with Simon's theory of bounded rationality, where individuals make decisions based on limited information and within their cognitive constraints. The responses indicate a clear need for more structured, accessible educational resources, professional support, and centralized information to alleviate the burden on caregivers and improve their decision-making processes. This theme underscores the importance of evidence-based policymaking to address these gaps and provide comprehensive support systems for informal caregivers, guiding my holistic coding approach to ensure these critical issues are highlighted and addressed in the analysis.

#### ***Question 24***

The 8th question in this survey, labeled, Q24, asks "Reflecting on your experience of providing end-of-life care, can you tell me about how this experience has shaped your thoughts and feelings about life and dealing with challenging situations?" To analyze the responses to Q24, I applied the codes of Profound Emotional Stress, Caregivers' Perceptions, and Decision-Making Process to categorize the data. The code of Profound

Emotional Stress reflects the intense emotional experiences caregivers face, such as grief, guilt, and frustration. Many respondents expressed profound feelings of guilt and regret, as illustrated by Respondent 5, who said, “I feel guilty he didn’t die in a hospital,” and Respondent 6, who shared, “I just want to make my grandma proud and feel like I didn’t do a very good job.” Intense grief and sadness were also common, with Respondent 9 stating, “I don’t know. Maybe just sad that you spend your whole life with someone and at the end it just felt like I should have done more,” and Respondent 2 admitting, “I think I am more angry and less forgiving because I was so frustrated with the death.” These responses highlight the significant emotional toll caregiving takes on individuals, underscoring the need for comprehensive emotional support systems and grief counseling for caregivers.

The code *Caregivers’ Perceptions* captures how caregiving experiences shaped their views on life, relationships, and the caregiving process itself. Respondents frequently mentioned a deeper appreciation for life’s fragility and increased empathy. For instance, Respondent 3 remarked, “Providing end-of-life care for my husband has profoundly shaped my thoughts and feelings about life and coping with adversity. The intense grief I’ve experienced has made me acutely aware of life’s fragility and the preciousness of every moment.” Similarly, Respondent 16 noted, “Reflecting on my experience of providing end-of-life care for my mother has profoundly shaped my thoughts and feelings about life and dealing with challenging situations.” The experiences also heightened respondents’ resilience and empathy, with Respondent 7 stating, “It has made me more acutely aware of the fragility and preciousness of life, instilling a deep

sense of empathy and compassion for others facing similar trials,” and Respondent 15 adding, “Going through such a hard time taught me that even when things are tough, you have to keep going and do your best, no matter how much it hurts.” These reflections emphasize the transformative impact of caregiving on individuals’ perspectives and the critical importance of emotional and practical support.

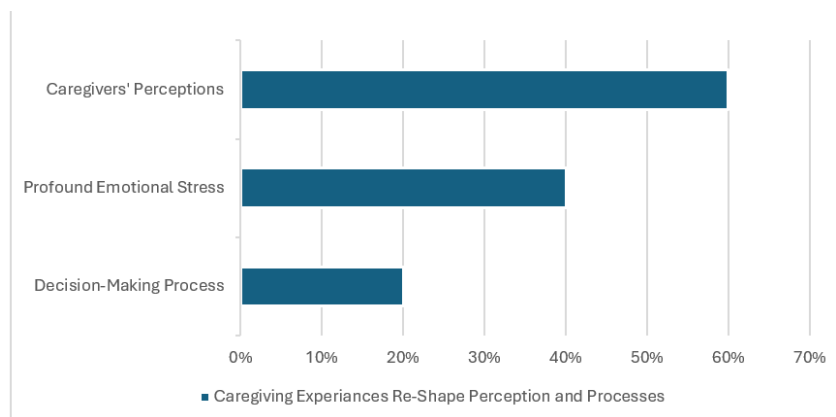
Lastly, the code *Decision-Making Process* highlights the reflections on the decision-making process, including regrets, lessons learned, and the importance of seeking support. Many respondents acknowledged the need for more information and support during the caregiving process. Respondent 10 expressed, “I need to ask more questions, I wish I could do it all again,” and Respondent 12 stated, “I think you just have to reach out more and talk to more people, but we just didn’t know where to go.” Preparedness and regret were also significant themes, as Respondent 18 reflected, “It has made me realize how totally unprepared I was but rose to the occasion and feel I can help others who are going through this a little better now.” Ethical concerns were voiced by Respondent 13, who shared, “I think I will speak out more. I guess what I think is not ethically right and what is just convenient for medicine when people go into hospice. My mom couldn’t speak for herself and she was drugged to death.” These responses highlight the complexity and difficulty of making critical decisions in caregiving, emphasizing the need for better information, preparedness, and ethical considerations in end-of-life care decisions.

Figure 8 illustrates the percentage of respondents who reported various impacts of caregiving experiences on their perception and decision-making processes. Categories

include decision-making, profound emotional stress, and caregivers' perceptions.

**Figure 8**

*Caregiving Experiences Re-Shape Perception and Processes*



The bar chart reveals that caregivers frequently reported experiencing profound emotional stress, with 10 instances reflecting intense feelings of grief, guilt, anger, and sadness, exemplified by comments like “I feel guilty he didn’t die in a hospital” and “I just want to make my grandma proud and feel like I didn’t do a very good job.” The highest frequency of responses, 15 instances, fell under Caregivers’ Perceptions, showing how their experiences profoundly shaped their views on life, relationships, and the caregiving process, such as one caregiver’s remark, “Providing end-of-life care for my husband has profoundly shaped my thoughts and feelings about life and coping with adversity.” Additionally, the Decision-Making Process category, with 5 instances, highlighted the challenges caregivers faced and the lessons learned, including the need for more information and support, feelings of unpreparedness, and ethical concerns, as one respondent noted, “I need to ask more questions, I wish I could do it all again.” This visual representation helps convey how these experiences have shaped caregivers’



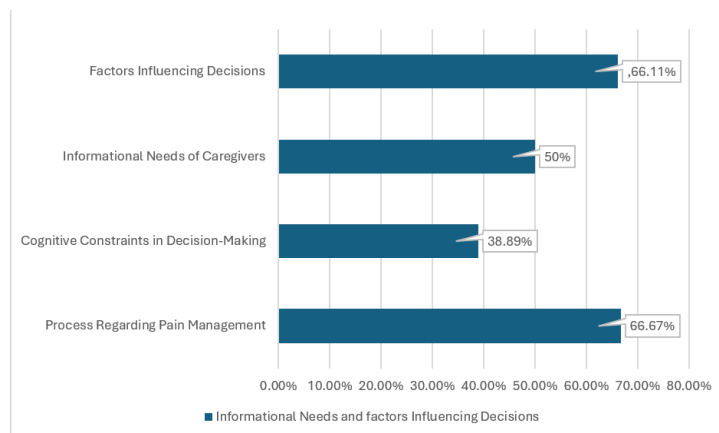
### ***Question 25***

The 9th question in this survey, labeled Q25, asked, “If you had experiences deciding on pain management or comfort care options for your loved one’s comfort, how did you make those decisions, and what information sources guided you?” This question was aimed to explore the informational needs and factors that influence the decisions informal caregivers make when providing end-of-life care. To analyze the responses to Q25, I coded the data into four primary categories: Process Regarding Pain Management or Comfort Care, Cognitive Constraints in Decision-Making, Informational Needs of Caregivers, and Factors Influencing Their Decisions.

Figure 9 illustrates the percentage of respondents who reported various informational needs and factors influencing their decision-making processes during end-of-life care. Categories include factors influencing decisions, informational needs of caregivers, cognitive constraints in decision-making, and the process regarding pain management.

**Figure 9**

### ***Informational Needs and Factors Influencing Decisions***



The *Process Regarding Pain Management or Comfort Care* was mentioned 12 times, reflecting the deeply emotional and challenging nature of making these decisions. For instance, Respondent 3 shared, “Making decisions about pain management and comfort care for my loved one was a deeply emotional and challenging process. I relied on a combination of information sources to guide these decisions.” Similarly, Respondent 4 emphasized the importance of professional guidance, stating, “When deciding on pain management and comfort care options for my husband, I relied heavily on the guidance of Hospice nurses and the information they provided.”

Cognitive Constraints in Decision-Making appeared 7 times, highlighting the stress and uncertainty caregivers felt during the decision-making process. Respondent 5 expressed this clearly: “I did the best I could but I would have been better if I was a nurse or if I knew more. I felt like I didn’t know what I was doing and that all I could think of.” Respondent 6 echoed this sentiment, admitting, “I just did what they said because I was way too stressed.” These responses illustrate the significant cognitive challenges caregivers faced, often feeling overwhelmed and ill-prepared to make critical decisions.

The category of *Informational Needs of Caregivers* was mentioned 9 times, underscoring the critical role of information in caregiving. Respondent 7 described their reliance on professional consultations, stating, “When deciding on pain management and comfort care options for my brother, I relied heavily on consultations with his healthcare team, including doctors and palliative care specialists.” Meanwhile, Factors Influencing Their Decisions, mentioned 11 times, revealed how personal experiences and preferences shaped caregivers’ choices. Respondent 8 shared, “After watching my father pass away

and being in so much pain, I knew better than to let my mom suffer that way,” highlighting how past experiences profoundly influenced their decisions. These insights emphasize the complex interplay of emotional stress, cognitive limitations, informational needs, and personal factors in the decision-making processes of caregivers.

### *Questions 26 and 27*

The tenth question in this survey, labeled, Q26, asked “Reflecting on your perceptions of end-of-life care, how did any decisions regarding pain management or comfort care affect you emotionally?” The eleventh question in this survey, labeled, Q27, asked “Please describe any concerns or feelings of guilt associated with those decisions and how you coped with those feelings.”

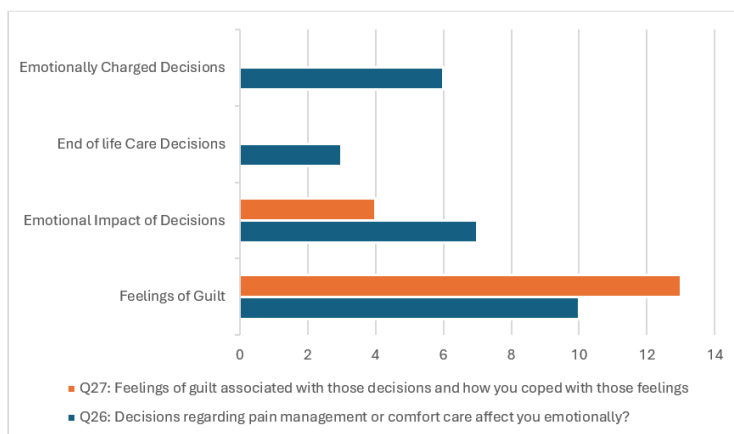
To analyze the responses to Q26 and Q27, I applied specific coding to categorize the data into four primary categories: Feelings of Guilt, Emotional Impact of Decisions, End-of-Life Care Decisions, and Emotionally Charged Decisions. The responses revealed that feelings of guilt were prevalent, with 10 out of 18 respondents expressing this emotion. For instance, Respondent 1 shared, “A little guilty and selfish because when pain medication was given it was the only time I could rest,” and Respondent 4 noted, “I often felt a deep sense of guilt and anxiety about whether I was doing the right thing for my husband.” These responses highlight the pervasive nature of guilt in caregiving, particularly regarding pain management decisions.

Seven out of 18 respondents discussed the emotional impact of their decisions. Respondent 3 explained, “Each decision shaped my grieving process, reinforcing the complexity and depth of emotions involved in caregiving during the end-of-life journey,”

while Respondent 4 stated, “Understanding and accepting the necessity of these choices helped me process my grief and begin to heal emotionally.” These reflections underscore the profound emotional toll that caregiving decisions can have, often leaving caregivers feeling overwhelmed and emotionally drained.

End-of-Life Care Decisions and Emotionally Charged Decisions were also prominent in the responses. Three respondents explicitly mentioned the impact of their end-of-life care decisions, such as Respondent 13, who said, “I regret not speaking up about the morphine because I think that’s what killed her in the end.” Six respondents described their decisions as emotionally charged, with Respondent 14 expressing, “The decisions regarding pain management or comfort care left me emotionally wrecked and furious at times.” These responses illustrate the intense emotional struggles involved in making end-of-life care decisions, emphasizing the need for better support systems to help caregivers navigate these challenging and emotionally taxing situations.

Figure 10 illustrates the number of respondents who reported various emotional impacts of their caregiving decisions. It compares the responses to two questions: Q26 (decisions regarding pain management or comfort care and their emotional impact) and Q27 (feelings of guilt associated with those decisions and how caregivers coped with those feelings). Categories include feelings of guilt, the emotional impact of decisions, end-of-life care decisions, and emotionally charged decisions.

**Figure 10***Emotional Impact of Caregiving Decisions*

The data from Q26 and Q27 highlights the profound emotional impact and pervasive feelings of guilt associated with end-of-life care decisions. A significant number of respondents (13 out of 18) expressed feelings of guilt, indicating that guilt is a common and deeply felt emotion in caregiving. Additionally, many respondents (7 out of 18) discussed the emotional impact of their decisions, reflecting the heavy emotional toll of caregiving responsibilities.

The analysis also reveals that emotionally charged decisions (6 out of 18) and end-of-life care decisions (3 out of 18) are critical components of the caregiving experience, further emphasizing the need for comprehensive emotional and informational support for caregivers. Understanding these emotional dynamics can guide the development of policies and educational programs to provide better support for caregivers, ultimately enhancing their well-being and the quality of care they provide.

*Question 28*

The twelfth and final question in this survey, labeled, Q28, asked “Reflecting on your journey as a caregiver during end-of-life care, considering the support you received, the decisions you made, and the emotional impact it had on you, tell me how you envision carrying forward the lessons learned and experiences gained from this caregiving experience in your life moving forward.” To analyze the responses to Q28, I used direct quotes from participants to create codes that best represent their experiences. I categorized the data into five primary codes: Decisions, Support, Emotional Impact, Caregiving Experience, and Guilt and Grief. For example, Respondent 3 emphasized the importance of both Decisions and Support, stating, “Carrying forward the lessons learned and experiences gained from my caregiving journey is a deeply personal and reflective process for me. I intend to cherish every moment with my family and loved ones, understanding the fragility and preciousness of life.” Similarly, Respondent 4 reflected on the Emotional Impact and Support, noting, “Making these choices was incredibly stressful, and I often felt a deep sense of guilt and anxiety about whether I was doing the right thing for my husband.”

The frequency of each code highlights the predominant patterns in the responses: Emotional Impact (10 instances), Support (8 instances) Decisions (8 instances), Caregiving Experience (7 instances), and Guilt and Grief. (6 instances). Respondent 15 encapsulated several of these patterns by sharing, “Reflecting on my journey as a caregiver during my sister’s end-of-life care, I’ve learned a lot of hard lessons that I’ll carry with me. The support I received, though limited, taught me the importance of

asking for help and accepting it when it's offered. These insights reveal the profound emotional toll and the necessity of strong support systems, as well as the complex decision-making processes and lingering feelings of guilt that caregivers endure.

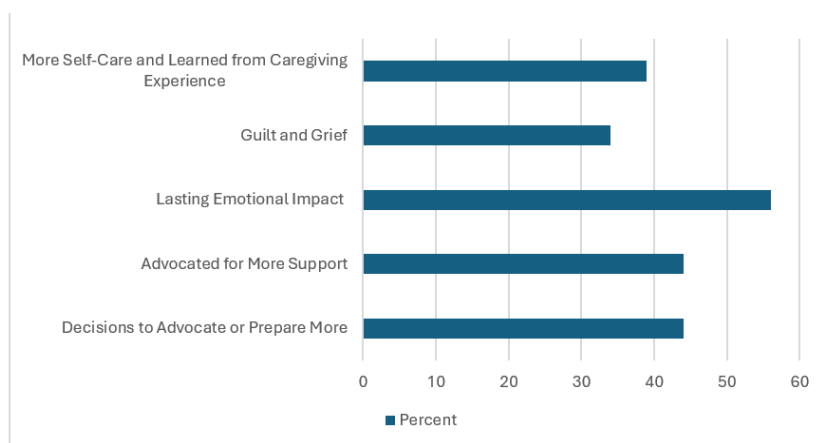
Overall, the data indicates that caregivers frequently experience intense emotional impacts from their caregiving roles, highlighting the need for emotional support and resources. For example, Respondent 5 shared, "It changed me forever. I will never not feel bad about the way he died," demonstrating the lasting emotional effects of caregiving. Additionally, the importance of decision-making and support was emphasized, with Respondent 14 stating, "Reflecting on my journey as a caregiver during end-of-life care, I am acutely aware of the profound lessons and experiences that will shape my life moving forward." These responses underscore the significant emotional burden and the critical need for comprehensive support systems to help caregivers navigate their roles and responsibilities effectively.

My analysis of the data for Q28 responses involved evaluating the frequencies of five primary categories: Decisions, Support, Emotional Impact, Caregiving Experience, and Guilt and Grief and was based on in vivo coding, where direct quotes from participants were used to identify and categorize their experiences. For example, Respondent 3 emphasized the importance of making informed decisions and advocating for better support systems, while Respondent 1 highlighted the critical need for seeking and accepting support. For example, Respondent 3 emphasized the importance of making informed decisions and advocating for better support systems, stating, "I aim to advocate for improved support and resources for caregivers, drawing from my own challenges and

experiences. This includes promoting better access to information, financial assistance, and emotional support networks for families navigating similar situations.” Respondent 1 highlighted the critical need for seeking and accepting support: “No one can carry your grief. It’s important to ask for help when we need it. I hope others find help, I am fortunate that I have loved so deeply.” Another participant, Respondent 4, reflected on the journey, noting, “I have learned the critical value of seeking and accepting support, understanding that it is not a sign of weakness but a necessary part of navigating challenging times. Moving forward, I intend to advocate for better resources and support systems for caregivers.” These direct quotes illustrate the significant impact of decision-making and the essential role of support systems in the caregiving experience and determine the categories in Figure 11.

**Figure 11**

*Impact of Informal Caregiving Experiences*



The analysis of Q28 responses reveals that Emotional Impact was the most frequently mentioned theme, with 55.56% of caregivers discussing the profound



emotional toll of their experiences, such as Respondent 2, who hoped never to go through caregiving again, and Respondent 12, who reflected on the deep sadness and grief associated with their journey. Support and Decisions were equally significant, each mentioned by 44.44% of respondents. Caregivers frequently reflected on the decisions they made about health care preferences and end-of-life wishes, emphasizing the need for better resources and advocacy, as seen in Respondent 9's desire to avoid leaving their children in a difficult position. Support was another critical theme, with many caregivers acknowledging the importance of seeking and accepting help, like Respondent 4's plan to advocate for better caregiver support systems. The bar chart also highlights the Caregiving Experience (38.89%) and Guilt and Grief (33.33%), illustrating the lessons learned, the importance of self-care, and the emotional burden of guilt and grief, exemplified by Respondent 5's ongoing guilt about their loved one's death and Respondent 15's struggle with the tough decisions made about pain management. This visual representation underscores the multifaceted nature of caregiving and the critical need for comprehensive support systems to address these challenges.

#### **Theme 4: Hastening Death? Morphine-Related Guilt**

Beyond the themes derived from specific survey questions, an additional theme emerged directly from the caregivers' responses. They frequently expressed major concerns and coping mechanisms related to the fear and guilt associated with using morphine in end-of-life care. Although this issue wasn't explicitly addressed in the survey, its frequent mention highlighted its significant impact on caregivers' emotional well-being. One particularly challenging aspect of caregiving was the use of morphine

and other potent medications to manage pain at the end of life. Caregivers often experienced significant guilt and fear that administering these medications might hasten their loved one's death, adding another layer of emotional complexity to their caregiving experience. The following analysis representation provides insights into the emotional challenges faced by informal caregivers.

Direct quotes from respondents illustrate this struggle: "I often worried that giving morphine might hasten my loved one's death. This was a huge source of guilt for me" (Respondent 5) and "Dealing with the thought that morphine could speed up the dying process was very difficult. I sought counseling to cope with these feelings" (Respondent 12) (Q21). The emotional impact of pain management decisions was significant. Many caregivers expressed concerns about whether their actions were hastening death. One respondent shared, "The biggest concern for me was whether I was shortening their life by administering morphine. This thought haunted me, but I coped by reminding myself that their comfort was the priority" (Respondent 3). Another echoed this: "There were moments when I felt like I was playing God by deciding the morphine dose. The fear that I might be hastening their death was overwhelming" (Respondent 7). The weight of these decisions is further highlighted by another caregiver who said, "Reflecting on the decisions about pain management, I couldn't shake off the feeling that I might have quickened their death. This guilt was very heavy on my heart" (Respondent 9) (Q26 & Q27).

To cope with these feelings of guilt and concern, informal caregivers used various strategies. One respondent explained, "I joined a support group specifically for caregivers

dealing with end-of-life decisions. Hearing others talk about their fear of hastening death with morphine helped me process my own guilt” (Respondent 2). Professional counseling also played a crucial role, as noted by another caregiver: “Professional counseling was crucial. My therapist helped me understand that the primary goal was to alleviate pain, even if there were risks involved” (Respondent 8). Additionally, reassurance from healthcare professionals was significant: “The hospice nurse assured me that morphine, when used correctly, doesn’t hasten death. This knowledge helped, but the guilt was still there” (Respondent 11). Another caregiver reflected, “I felt immense relief when they weren’t in pain, but every dose came with the fear that I was speeding up their passing. This was a difficult balance to manage” (Respondent 4). Discussing these concerns with the healthcare team helped many realize the importance of prioritizing comfort, as one noted, “Discussing these concerns with the healthcare team helped me realize that keeping my loved one comfortable was the most important thing, even if it meant facing my fears about hastening death” (Respondent 6), (Q21, Q26 & Q27). These insights underscore the importance of holistic support systems in helping caregivers manage the emotional challenges associated with end-of-life care decisions.

This key theme of *Hastening Death? Morphine-Related Guilt* in the caregivers’ data is essential to my study as it highlighted significant emotional challenges and guilt associated with using morphine in end-of-life care, aligning with the literature in Chapter 2 that emphasizes the need for education and support to address misinformation and emotional distress. Both sources underscore the importance of comprehensive support systems for caregivers to manage these complex emotions effectively.

### **Summary of Combined Data**

This qualitative research examined the impact of education and policy on the experiences of informal caregivers dealing with grief and guilt during end-of-life care. An online survey found that while 52% of respondents identified some effective support systems such as hospice care, emotional support from family and friends, and online support groups, these were often deemed insufficient. Respondents highlighted the need for more comprehensive financial assistance, emotional and mental health support, robust caregiver training, and respite care services. Additionally, many caregivers faced significant challenges in navigating the healthcare system, further exacerbating their stress and feelings of isolation.

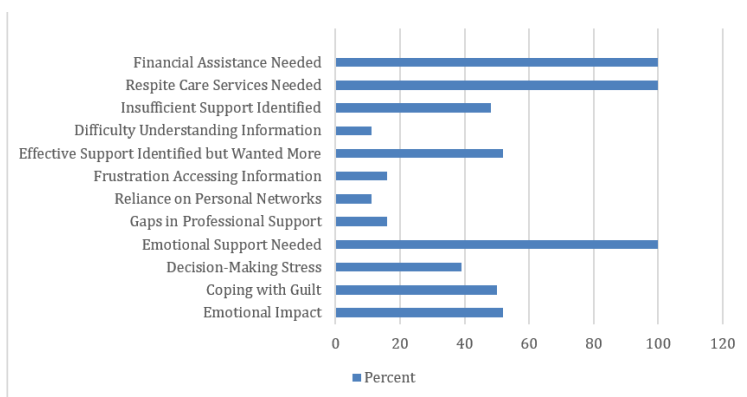
The emotional burden on caregivers was profound, with many reporting intense feelings of guilt, grief, and frustration. These emotions were often linked to the cognitive constraints they experienced, such as difficulty understanding medical information and making decisions under emotional strain. The inductive analysis process revealed four key themes emphasizing the critical need for accessible and professional support systems. For instance, respondents noted the invaluable role of hospice nurses and the necessity of clear, compassionate guidance in managing their caregiving responsibilities.

Figure 12 illustrates the percentage of respondents who reported various experiences and needs during caregiving. Categories include financial assistance needed, respite care services needed, insufficient support identified, difficulty understanding information, effective support identified but wanted more, frustration accessing information, reliance on personal networks, gaps in professional support, emotional

support needed, decision-making stress, coping with guilt, and emotional impact.

**Figure 12**

*Synthesis of Informal Caregivers' Experiences and Needs*



Synthesizing the data with the research question and relevant theories, the research highlights the principles of Simon's Bounded Rationality Theory, illustrating how caregivers make "satisficing" decisions due to cognitive constraints. For example, 38.89% of caregivers reported difficulties in decision-making due to stress and lack of knowledge. The evidence-based policymaking approach is reinforced by the caregivers' need for clear, accessible information and professional guidance, as indicated by 50% of respondents who expressed the necessity for better informational resources. Furthermore, emotional and professional support, such as hospice care and educational interventions, were shown to significantly alleviate caregivers' stress and improve their ability to provide care. To address these challenges, the findings suggest enhancing support services and developing comprehensive, culturally sensitive educational programs tailored to caregivers' needs.

## Summary

In this chapter, I identified four themes that encapsulated the challenges and emotional burdens faced by informal caregivers in end-of-life care: Challenges with Accessing and Timeliness of Support Resources, Psychological Impact and Enduring Guilt, Information and Decision-Making Constraints, and Hastening Death. Morphine-Related Guilt. Caregivers often struggled to find adequate support and resources, despite their availability. The lack of accessible and timely support exacerbated their stress, hampering their ability to provide optimal care. They operated under significant cognitive constraints, making critical decisions under stress and with limited information.

Effective policies and educational programs played a pivotal role in shaping their decision-making processes and alleviating some of the cognitive burdens by providing clear, accessible information and guidance. The emotional toll of caregiving, especially regarding decisions about pain management and end-of-life care, was immense. Caregivers frequently grappled with deep feelings of guilt and emotional distress, questioning whether they had made the right choices. This enduring guilt significantly impacted their mental health and well-being. A particularly challenging aspect of caregiving was the administration of morphine and other potent medications. Caregivers often felt significant guilt and fear that these medications might hasten their loved one's death, adding another layer of emotional complexity to their caregiving experience.

Simon's theory of bounded rationality suggested that individuals made decisions based on limited information and cognitive constraints, often settling for satisfactory rather than optimal outcomes. This theory was highly relevant to the caregiving context,

where caregivers had to make crucial decisions under stressful conditions with limited knowledge and resources. The themes I identified in this chapter highlighted these cognitive constraints and the resulting emotional burdens. Difficulty accessing support and resources reflected Simon's bounded rationality, as caregivers often had to make do with inadequate support, leading to suboptimal caregiving outcomes. Cognitive constraints and the influence of policy and educational support aligned with the notion that better information and structured support could help mitigate the effects of bounded rationality. The profound emotional impact and enduring guilt associated with decision-making highlighted the emotional toll of bounded rationality, where caregivers' decisions, made under stress and with limited information, led to significant emotional distress and guilt. The fear and guilt tied to the use of morphine demonstrated the specific emotional complexities and cognitive constraints in administering end-of-life care.

In Chapter Five, I present recommendations and strategies to address the challenges identified in the previous chapters, providing a roadmap for creating more effective and compassionate support systems for informal caregivers. By synthesizing the data collected in this study with existing literature, I aim to demonstrate how education and policy could enhance the support and resources available to caregivers. Additionally, Chapter 5 shows how the findings of this study could contribute to broader social change.

## Chapter 5: Discussion, Conclusions, and Recommendations

The purpose of my study was to understand how education and policy impact the experiences of informal caregivers dealing with grief and guilt in end-of-life care. I explored how these policies influence caregivers' emotional journeys and how education can support them. Specifically, I sought to answer the question: "What do the grief and guilt experiences of informal caregivers reveal that would guide policy change for education on end-of-life care?"

I conducted this study using a generic qualitative approach, focusing on the distinct challenges and cognitive limitations informal caregivers face. I collected data from a group of participants through an online survey to capture a wide range of informal caregiving experiences. This research was driven by the lack of evidence on how education on end-of-life care affects the grief and guilt process of informal caregivers. My findings aimed to inform policy changes that could provide better support and education for caregivers, ultimately causing social change by improving informal caregivers' emotional well-being and the quality of care they provide.

### **Key Findings Summary**

In my research on how education and policy affect the experiences of informal caregivers dealing with grief in end-of-life care, several key findings emerged. By analyzing diverse participant demographics, ranging from various age groups, genders, and socioeconomic statuses, I expanded a comprehensive view of the unique challenges and needs of informal caregivers. This diversity in participant backgrounds provided rich data that underscored the complexities inherent in informal caregiving.



One of the main findings was how the informal caregivers perceived healthcare support concerning pain management at end-of-life care and how they utilized support such as hospice care and emotional support from family and friends. However, these support mechanisms, although available, were frequently deemed insufficient or untimely by the informal caregivers. Many participants expressed a need for more comprehensive financial assistance, emotional and mental health support, robust caregiver training, and respite care services. Difficulty navigating the healthcare system was a recurring pattern, adding to the stress during high-pressure decision-making and feelings of isolation when they experienced a lack of support. These insights highlighted significant gaps in the current support structures available to informal caregivers, pointing to the necessity for systemic improvements in the access and application of support services.

The emotional burden on informal caregivers was another finding. Participants reported intense feelings of guilt, grief, and frustration. The cognitive constraints they faced, such as difficulty in understanding medical information and making decisions under emotional strain, were significant barriers. Informal caregivers employed a variety of coping mechanisms, including relying on social support, engaging in physical activities, practicing spiritual rituals, seeking professional counseling, and developing personal coping strategies. However, the effectiveness of these mechanisms varied, often leaving informal caregivers struggling to manage their emotional turmoil.

The decision-making process for caregivers was also a focal point of my analysis and confirmed the knowledge found in the literature review in Chapter 2. The themes of challenges with accessing and timeliness of support resources, psychological impact and

enduring guilt, information and decision-making constraints, and hastening death? morphine-related guilt emerged from the data. It was evident that the availability and quality of support and information significantly influenced informal caregivers' decisions. Many relied on the guidance of healthcare professionals, yet this support was not always sufficient or timely, highlighting the need for better educational resources and professional advice.

### **Interpretation of the Findings**

Integrating these findings with my theoretical framework, Simon's bounded rationality theory, I illustrate and extend the knowledge about how informal caregivers made "satisficing" decisions due to cognitive constraints. This theory, combined with EBPM principles, underscored the necessity for clear, accessible information and professional guidance. My study revealed that emotional and professional support systems could significantly alleviate informal caregivers' stress and improve their ability to provide care.

A particularly notable theme that emerged from my research was informal caregivers' fear and guilt or their resentment toward healthcare providers associated with the use of morphine in end-of-life care. Many informal caregivers expressed concerns about the potential of morphine to hasten death, adding a significant emotional burden. This fear was compounded by guilt, as caregivers grappled with the moral implications of their decisions. For example, one caregiver shared, "I often worried that giving morphine might hasten my loved one's death. This was a huge source of guilt for me," while another noted, "Dealing with the thought that morphine could speed up the dying process

was very difficult. I sought counseling to cope with these feelings.” These findings underscore the need for targeted education to address the widespread misinformation surrounding morphine in palliative care. Many informal caregivers were not adequately informed about morphine’s role in pain management, leading to unnecessary fear and guilt which, in turn, resulted in resentment toward the healthcare providers. The literature supports and confirms these findings, highlighting significant misinformation even among healthcare professionals, further complicating caregivers’ emotional experiences (Hidalgo-Andrade & Mascialino, 2022).

To cope with these feelings, some informal caregivers sought reassurance from healthcare professionals and participated in support groups or professional counseling which extended and confirmed the need for improved support from healthcare providers. For instance, a respondent mentioned, “The hospice nurse assured me that morphine, when used correctly, doesn’t hasten death. This knowledge helped, but the guilt was still there.” These insights highlight the necessity for comprehensive support systems that provide accurate information and robust emotional support, helping caregivers make informed decisions without the added weight of fear and guilt. Informal caregivers who did not have this type of support experienced guilt and grief differently, aligning their resentment toward the healthcare providers for what was their perception of causing death sooner with the use of morphine or pain management medications. These results align with broader literature recommendations for comprehensive and empathetic support systems for informal caregivers in end-of-life care (Clarke & Seymour, 2010; Martz & Morse, 2016; Stroebe et al., 2014).

### **Synthesizing Literature with Data**

The data collected from respondents highlights significant gaps in accessing consistent support and resources for informal caregivers during end-of-life care. This aligns with the principles of EBPM as described by Hasani (2019), emphasizing the need to understand the real-world impact of policies and programs on caregivers. By analyzing these responses, I identified critical areas where support is lacking or inconsistent and that there is a need to develop policies that address these needs effectively. Several key areas of missing support were identified by the respondents. These include the needs for more help and guidance, the lack of professional caregiving support, financial assistance, respite services, emotional and mental health support, proper medical advice, cultural and language barriers, formal training and education, and specialized informal caregiving support. For instance, one respondent noted, “The absence of consistent professional caregiving support. Emotional support was another critical area where I felt unsupported” (Respondent 3). Another respondent shared, “During my brother’s most intense moments of need, I felt acutely the absence of respite services and additional professional support” (Respondent 7).

The absence of professional caregiving support and respite services was frequently mentioned. Respondents expressed the need for consistent professional assistance to provide a respite and allow them to focus on other aspects of their lives, such as maintaining their jobs and supporting their children (Respondents 3, 6, 7, 16). This finding underscores the importance of integrating more robust caregiver training and respite care services, which Clarke and Seymour (2010) advocated for in their call for

comprehensive support systems for caregivers. Financial assistance and emotional support were also significant areas where caregivers felt unsupported. Respondents highlighted the financial strain of caregiving and the constant worry about affording necessary medications and treatments. One respondent emphasized, “More comprehensive financial assistance would have alleviated the constant worry about affording his medications and treatments” (Respondent 4). This aligns with Garcia’s (2018) emphasis on the need for policies that recognize and address the economic burdens faced by caregivers.

The lack of formal training and education on end-of-life care was another critical gap I identified. Respondents expressed feeling unprepared and overwhelmed due to the absence of proper training, which made it difficult for the informal caregivers to manage care and symptom management effectively. One respondent remarked, “A comprehensive training program on end-of-life care would have provided me with the knowledge and confidence to handle these situations more effectively” (Respondent 16).

Additionally, the need for culturally sensitive care and language support was highlighted by respondents who faced language barriers and cultural insensitivity from healthcare providers. One respondent stated, “Miscommunications about medical instructions, treatment plans, and medication details were common” (Respondent 14). This indicates the necessity for policies that ensure culturally competent care and reliable access to professional medical interpreters. The responses indicate significant gaps in support and resources for caregivers who need more comprehensive and culturally sensitive policies.

## **Recommendations**

I recommend addressing these gaps through targeted policies that could significantly enhance the support available to informal caregivers, making the caregiving process more manageable and less emotionally taxing. This recommendation aligns with the broader literature's recommendations for comprehensive policy solutions that address caregivers' emotional and practical needs (Clarke & Seymour, 2010; Garcia, 2018). My analysis aligns with the need for more accessible and comprehensive end-of-life care education, as emphasized by Breen and O'Connor (2007) and Hidalgo-Andrade and Mascialino (2022). The responses highlight the limitations caregivers face in accessing and processing information, underscoring Simon's concept of bounded rationality (1972). I recommend more effective educational resources and professional support that are more effective at ensuring caregivers have the knowledge and confidence to provide the best possible care. As one respondent noted, "Guidance from hospice nurses was invaluable" (Respondent 4), reflecting the importance of professional support. Addressing these gaps through targeted policies could significantly enhance the support available to informal caregivers, aligning with the broader literature's recommendations for comprehensive policy solutions (Clarke & Seymour, 2010; Garcia, 2018).

Theme 2, the psychological impact and enduring guilt are confirmed, emphasizing the need for more accessible and comprehensive end-of-life care education, as highlighted by Breen and O'Connor (2007) and Hidalgo-Andrade and Mascialino (2022). The responses highlight the limitations informal caregivers face in accessing and processing information, underscoring Simon's concept of bounded rationality (1972).

Effective educational resources and professional support are crucial in addressing these gaps, ensuring caregivers have the knowledge and confidence to provide the best possible care. As one respondent noted, “Guidance from hospice nurses was invaluable” (Respondent 4), reflecting the importance of professional support. Additionally, addressing technological and cultural barriers is essential for making information more accessible to all caregivers. The responses indicate significant challenges in accessing clear, reliable information and support, highlighting the need for comprehensive and culturally sensitive educational resources.

The combined data from Q20 and Q21 responses reveals that caregivers employed various personal coping strategies, including reliance on social support, engaging in physical activities, spiritual practices, professional counseling, and routine maintenance. Notably, there is a consistent use of substance use as a coping mechanism across both Q20 and Q21, reflecting the need to address potentially risky behaviors. Specifically, in making decisions about pain management for their loved ones, caregivers relied on educational and professional support, spiritual practices, and self-reflection to manage associated guilt and grief. These insights will be instrumental in developing targeted support interventions and systems that acknowledge the full spectrum of coping strategies used by informal caregivers, from health-promoting activities to potentially risky behaviors. Gaining such insights is crucial for formulating policies and educational programs that robustly support the well-being and resilience of informal caregivers (Stein & Fineberg, 2013; Vargas-Escobar et al., 2022).

The feedback from caregivers underscores the significant role of cognitive

constraints, as evidenced by the high frequency of mentions in Q23 (14 instances). Caregivers often felt overwhelmed, experienced second-guessing, and dealt with lingering guilt and doubt, reflecting the emotional aftermath of their decisions. This aligns with Schaathun's (2022) emphasis on the cognitive limitations that affect decision-making under stress. Conversely, the data also highlights the critical role of policy and educational support in influencing caregiving decisions. In Q22, caregivers frequently mentioned the positive impact of support from healthcare professionals and educational resources (11 instances). This support provided reassurance, clarity, and confidence, helping caregivers navigate the complex decisions associated with end-of-life care. However, in Q23, the influence of policy and educational support was less frequently mentioned (2 instances), suggesting that caregivers felt the need for more consistent and impactful support during critical decision-making moments.

To address the findings from the data on Q19-Q23, I recommend establishing policies that ensure caregivers have consistent access to professional support and respite services. This would allow them to take necessary breaks and manage other responsibilities like work and family duties. Second, educational materials are reassessed by their institutions and made more comprehensive, accessible, and culturally sensitive, tailored specifically for informal caregivers. This includes creating more specific training programs on end-of-life care for hospitals, nursing homes, hospice providers, and home care agencies that can be tailored to boost in informal caregivers' knowledge and confidence in handling care and symptom management. Clear, consistent, and empathetic guidance will help caregivers make better decisions, reducing cognitive strain and



emotional distress. Healthcare providers may benefit from reassessing their desensitized approach to end-of-life care. My recommendations could create a more supportive and effective environment for informal caregivers, improving the quality of end-of-life care and addressing the significant gaps identified in the data.

Theme 3 covered Information and Decision-Making Constraints. My questions delved into the emotional and psychological aspects of caregiving, aligning with the literature's focus on the significant emotional burden caregivers experience (Stroebe et al., 2014; Martz & Morse, 2016). Data from Q24 reveals that 40% of caregivers (n=7) reported experiencing profound emotional stress, underscoring the significant toll that caregiving takes on individuals. This included intense feelings of grief, guilt, anger, and sadness, aligning with the literature (Stroebe et al., 2014; Martz & Morse, 2016) on the emotional burdens faced by caregivers.

The theoretical perspective of bounded rationality is evident in how caregiving experiences reshape caregivers' perceptions and decision-making processes. The data shows that 60% of caregivers' (n=11) responses fell under "Caregivers' Perceptions," indicating that caregiving profoundly influences their views on life, relationships, and the caregiving process itself. This supports the notion that caregivers operate under cognitive constraints, making decisions based on limited information and emotional pressure, as suggested by Simon's Bounded Rationality Theory (Schaathun, 2022). Additionally, the decision-making process was reflected in 20% of the responses (n=4), where caregivers expressed a need for more information and support, feelings of unpreparedness, and ethical concerns. These reflections highlight the complexity of decision-making in

caregiving and the critical need for better information and preparedness, aligning with the literature on informed consent and decision support (Mezey et al., 1997).

Focusing on Q25, the decision-making process regarding pain management or comfort care reflects Simon's Bounded Rationality Theory's emphasis on cognitive constraints in decision-making (Schaathun, 2022). The data reveals that 38.89% of respondents (n=7) indicated difficulties due to stress, lack of knowledge, and reliance on others for decision-making, highlighting the challenges caregivers face when processing complex information under emotional strain. Responses also emphasize the need for clear, accessible information and guidance, as 50% of caregivers (n=9) expressed a need for better informational resources. This is consistent with the literature underscoring the importance of comprehensive education and support to empower caregivers in their roles (Hidalgo-Andrade & Mascialino, 2022).

Furthermore, the data shows that 66.67% of respondents (n=12) were involved in the decision-making process regarding pain management or comfort care, reflecting the necessity of involving caregivers in informed decision-making. Additionally, 61.11% (n=11) of the responses highlighted various factors influencing their decisions, such as personal experiences, cultural beliefs, and the advice of healthcare professionals. These factors underscore the complexity of decision-making in caregiving and the need for a tailored approach that respects individual circumstances and preferences.

Exploring the emotional impact of decisions related to pain management or comfort care delves into the psychological experiences of informal caregivers, aligning with the literature on caregivers' emotional stress and guilt (Martz & Morse, 2016;

Stroebe et al., 2014). It acknowledges the emotional complexities of end-of-life care decisions, informed by bounded rationality in the face of emotionally charged decisions (Schaathun, 2022). The insights gained can inform the development of supportive resources and policies that address not only the informational but also the emotional needs of informal caregivers, facilitating a more holistic approach to end-of-life care planning and support. By understanding these profound emotional stresses and decision-making challenges, policies can be designed to provide better emotional and practical support, ultimately improving the caregiving experience and outcomes for caregivers and those they care for.

The final question, Q28, asked caregivers to reflect on their journey during end-of-life care, considering the support they received, the decisions they made, and the emotional impact it had on them. To analyze the responses, direct quotes from participants were used to create codes representing their experiences. The data was categorized into five primary codes: Decisions, Support, Emotional Impact, Caregiving Experience, and Guilt and Grief. For example, Respondent 3 emphasized both Decisions and Support, stating, “Carrying forward the lessons learned and experiences gained from my caregiving journey is a deeply personal and reflective process for me. I intend to cherish every moment with my family and loved ones, understanding the fragility and preciousness of life.”

Similarly, Respondent 4 reflected on the Emotional Impact and Support, noting, “Making these choices was incredibly stressful, and I often felt a deep sense of guilt and anxiety about whether I was doing the right thing for my husband.” The frequency of

each code highlights the predominant themes in the responses: Emotional Impact (10 instances), Support (8 instances), Decisions (8 instances), Caregiving Experience (7 instances), and Guilt and Grief (6 instances).

The findings underscore the intense emotional burden and complex decision-making processes faced by informal caregivers, often under conditions of limited information and high stress, as described by the concept of bounded rationality. The findings illuminate the emotional toll and complex decision-making processes faced by informal caregivers, often under conditions of limited information and high stress, as described by the concept of bounded rationality (Schaathun, 2022).

Reflecting the literature's emphasis on the substantial emotional stress caregivers face (Stroebe et al., 2014; Martz & Morse, 2016), I recommend targeted education on discussing death and the final stages of life. For instance, the development of an educational program that focuses on timely, comprehensible communication strategies for end-of-life conversations with informal caregivers early in the process and with repetition. The program could include training modules on how to initiate and navigate discussions about death, ensuring that both the healthcare provider and the informal caregivers are equipped with the knowledge and language needed to handle these sensitive topics. Incorporating role-playing exercises and scenario-based learning can help caregivers practice these conversations, fostering confidence and emotional preparedness. Additionally, providing clear, step-by-step guides and resources that caregivers can refer to in real-time can support them in delivering compassionate and informed care.

By focusing on enhancing communication skills and providing practical tools for discussing end-of-life matters, these educational initiatives align with the literature's emphasis on the need for comprehensive support systems that address both the emotional and cognitive needs of caregivers (Hidalgo-Andrade & Mascialino, 2022; Mezey et al., 1997). This approach can empower caregivers to manage caregiving's emotional and cognitive challenges more effectively, ultimately improving their well-being and the quality of care they provide.

Theme 4 covered the participants' perceptions about hastening death and the guilt related to morphine use in end-of-life care. Caregivers frequently expressed concerns and coping mechanisms related to the fear and guilt associated with administering morphine. Despite this issue not being explicitly addressed in my survey, its frequent mention highlighted its significant impact on caregivers' emotional well-being. Caregivers often experienced significant guilt and fear that administering these medications might have quickened their loved one's death, adding another layer of emotional complexity to their caregiving experience.

Respondents' direct quotes illustrate this struggle: "I often worried that giving morphine might hasten my loved one's death. This was a huge source of guilt for me" (Respondent 5), and "Dealing with the thought that morphine could speed up the dying process was very difficult. I sought counseling to cope with these feelings" (Respondent 12). Many informal caregivers expressed concerns about whether their actions were making death come faster. One respondent shared, "The biggest concern for me was whether I was shortening their life by administering morphine. This thought haunted me,

but I coped by reminding myself that their comfort was the priority” (Respondent 3).

To cope with these feelings of guilt and concern, informal caregivers used various strategies. One respondent explained, “I joined a support group specifically for caregivers dealing with end-of-life decisions. Hearing others talk about their fear of hastening death with morphine helped me process my own guilt” (Respondent 2). Professional counseling also played a crucial role, as noted by another caregiver: “Professional counseling was crucial. My therapist helped me understand that the primary goal was to alleviate pain, even if there were risks involved” (Respondent 8). These insights underscore the importance of holistic support systems in helping caregivers manage the emotional challenges associated with end-of-life care decisions.

This important emerging theme was crucial to my study as it emphasized the significant emotional challenges and guilt associated with using morphine in end-of-life care. This aligns with the literature in Chapter 2, which emphasized the need for education and support to address misinformation and emotional distress.”. Ho et al. (2020) reveal that morphine is often perceived as a drug of last resort, contributing to fears of hastening death and causing significant emotional distress among caregivers. This perception underscores the urgent need for better education and communication about the role of morphine in palliative care. Both sources underscore the importance of comprehensive support systems for caregivers to manage these complex emotions effectively.

### **Limitations to the Study**

Despite the valuable insights provided by this study, some limitations must be

acknowledged. While efforts were made to ensure a diverse sample, the findings may not entirely represent all informal caregivers' experiences in the USA. The sample's demographic characteristics may not accurately reflect the broader population of informal caregivers in the USA. For example, the sample had a higher proportion of older caregivers. It lacked sufficient representation from younger caregivers and various ethnic backgrounds, which could limit the generalizability of the results to the broader population of caregivers.

Another limitation is the sample concentration, as most participants were from a specific demographic and used LinkedIn and social media platforms. This technological bias might influence the findings and limit their applicability to informal caregivers in different parts of the country. Additionally, the study's reliance on online recruitment methods may have excluded those without internet access or those less comfortable with digital communication, potentially skewing the sample towards more technologically adept individuals.

### **Recommendations for Future Research**

The data from my survey informs my recommendations for future studies into the application of educational programs targeting both healthcare professionals and caregivers are necessary to dispel myths and provide accurate information about opioid use in palliative care. Policies could focus on developing community-based support systems and educational initiatives that address the specific emotional and informational needs of informal caregivers. Additionally, personalized interventions should be created to help caregivers manage guilt and bereavement, ensuring they receive the emotional

support necessary to navigate the complexities of end-of-life care decision-making. In my opinion, these measures, supported by the data, will enhance health literacy, reduce unnecessary emotional distress, and improve the overall quality of caregiving in end-of-life scenarios, thus impacting social change.

To truly honor the strength and resilience of informal caregivers, future research must expand and deepen our understanding of their experiences, particularly in the context of quality of life and end-of-life care. Ensuring that all voices, especially those from underrepresented groups, are included will provide a more comprehensive understanding of caregiving realities. Longitudinal studies are essential to capture the evolution of caregivers' emotional journeys, revealing how grief, guilt, and the effectiveness of support systems change over time. For example, tracking caregivers' emotional and psychological states over several years can reveal how their needs and the effectiveness of support programs evolve. We must delve into the deeply personal fears and guilt associated with decisions like administering morphine and understand the moral dilemmas caregivers face. In-depth qualitative research can uncover the raw, unfiltered emotions and struggles that define the caregiving experience.

Educating healthcare workers about the newness of end-of-life care information to inexperienced caregivers is crucial. By recognizing this gap, healthcare professionals can pause and offer clear, compassionate guidance, ensuring caregivers understand and feel supported. This approach can drive social change by fostering empathy, improving caregiver education, and ultimately enhancing the quality of care and support provided to those facing end-of-life challenges.



Culturally sensitive research is also crucial, as it helps to understand how cultural beliefs and practices influence caregiving, allowing for tailored support that resonates with diverse backgrounds. Evaluating specific educational interventions will identify what truly helps informal caregivers navigate their overwhelming responsibilities, providing them with the necessary knowledge and emotional fortitude. Furthermore, integrating technological tools, such as mobile apps and virtual counseling, can offer accessible, ongoing support, bridging critical gaps in care.

By addressing these research directions, we can drive social change that profoundly enhances the resilience and emotional well-being of informal caregivers. These changes can create a more compassionate and comprehensive support system, ensuring that informal caregivers are not left to navigate their challenging roles alone. Such policy and educational reforms can transform the caregiving experience, providing caregivers with the dignity, respect, and support they deserve, and ultimately leading to a more empathetic and effective end-of-life care system.

## **Implications**

### **Recommendations for Policy**

Based on evidence-based policymaking and Simon's bounded rationality theory, I recommend implementing comprehensive education programs targeting both healthcare professionals and caregivers to dispel myths and provide accurate information about opioid use in palliative care. Policy improvement could focus on developing more community-based support systems and educational initiatives that address more consistently the specific emotional and informational needs of informal caregivers.

Additionally, personalized interventions should be created to help caregivers manage guilt and bereavement, ensuring they receive the emotional support necessary to navigate the complexities of end-of-life care decision-making during all stages of informal caregiving – at the onset of care and beyond. These measures, supported by the data, will enhance health literacy, reduce unnecessary emotional distress, and improve the overall quality of informal caregiving in end-of-life scenarios.

The literature reviewed in Chapter 2 provided significant insights into morphine use, the hastening of death, and the intense grief experienced by caregivers in end-of-life care. Hidalgo-Andrade and Mascialino (2022) highlight the significant amount of misinformation surrounding the use of morphine in palliative care, even among healthcare professionals, emphasizing the need for education policies and interventions to enhance health literacy and positively influence how patients and caregivers perceive the use of opioids in end-of-life care. Clarke and Seymour (2010) stress the importance of education in helping informal caregivers deal with the challenges associated with grief and morphine use in palliative care, advocating for community-based approaches and educational programs tailored to the specific circumstances and needs of caregivers.

Martz and Morse (2016) delve into the emotional impact on family caregivers making treatment decisions, including the use of morphine, for parents nearing the end of life, underscoring the moral dilemmas families face and the need for specific policies and educational programs to support them. Stroebe et al. (2014) explore the intricate relationship between guilt and bereavement, particularly self-blame in the initial stages of grief, supporting the implementation of personalized interventions for caregivers to

address these complex emotions effectively. Additionally, Ho et al. (2020) reveal that morphine is often perceived as a drug of last resort, contributing to fears of hastening death and significant emotional distress among caregivers.

### **Positive Social Change**

This study has several implications for positive social change at individual, family, organizational, and societal levels. For individuals, the findings underscore the need for better emotional support and education for informal caregivers, which can enhance their well-being and caregiving abilities. Families can benefit from more robust support systems that alleviate the emotional and financial burdens of caregiving. Organizations, particularly healthcare providers, can implement better training and support programs for caregivers, ensuring they have the resources and knowledge necessary to provide effective care. At the societal level, policy changes informed by this research can lead to a more compassionate and comprehensive support system for informal caregivers, ultimately improving the quality of end-of-life care.

### **Conclusion**

In conclusion, this study highlights the critical need for improved education and policy support for informal caregivers dealing with grief and guilt in end-of-life care. The findings reveal significant gaps in the current support structures and underscore the importance of comprehensive, culturally sensitive, and accessible resources for caregivers. By addressing these needs through targeted policies and educational interventions, we can enhance the emotional well-being and caregiving abilities of informal caregivers, driving positive social change and improving the quality of end-of-

life care. The insights gained from this research provide a strong foundation for future studies and policy reforms, aiming to create a more supportive and empathetic environment for informal caregivers. and ultimately leading to a more empathetic and effective end-of-life care system – we can make a difference.

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## Appendix A: Flyer



Did you provide end-of-life care for a loved one?  
Have you experienced grief or guilt after providing care for a loved one who has passed away?

- Would you be interested in Participating in an online questionnaire for my PhD research study?
- Online survey will be conducted through this link: [suveymonkey.ca](http://suveymonkey.ca). You will remain completely anonymous with this study.



Participate

[xxx.surveymonkey.ca](http://xxx.surveymonkey.ca)

## Appendix B: Participant Welcome Letter

### **Welcome to my study...**

#### **This study seeks 30-45 volunteers who are:**

- Experienced informal caregiving at end-of-life care for a loved one.
- Experienced the loss of a loved one within the last 12 months but not sooner than three months.

This study is being conducted by a researcher named Brandan Margaret Rose, who is a doctoral student at Walden University. You might already know this researcher as a Nursing Home Administrator, but this study is separate from that role.

#### **Study Purpose:**

The purpose of this study is to learn more about what people who look after someone at the end of their life think about the rules and plans for helping them. It also wants to find out how learning about these things makes these caregivers feel.

The study will take a close look at the problems and things that are hard to understand for people who take care of others when they are dying. This will help us make sure that people who need help the most can get it.

#### **Procedures:**

This study will involve you completing the following steps:

- Complete an anonymous online survey (20 minutes).
- Review a typed transcript of your interview and make changes (10 minutes).

#### **Here are some sample questions:**

1. Reflecting on the time you spent caring for your loved one, please describe any support or resources you used and which ones made the biggest difference for you.
2. Tell me about when you felt you were missing support or resources and how these things would have made things easier.
3. Thinking of the difficult decisions you had to make regarding pain management and end-of-life comfort, what strategies did you use to cope with the guilt or grief associated with those decisions.

## Appendix C: Inclusion and Exclusion Criteria

### Inclusion Question 1

Preview & Test INVOKE

Copy of Caregiver EOL Survey

Informal Caregiver Survey

1. Did you provide care for someone at end-of-life? (Inclusion) ⌵

Yes

No

Next

Powered by **SurveyMonkey**  
See how easy it is to create surveys and forms.

### Inclusion Question 2

Preview & Test INVOKE

Copy of Caregiver EOL Survey

2. Have you experienced the loss of a loved one within the past 36 months but not sooner than 3 months. (Inclusion) ⌵

Yes

No

33%

Prev Next

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### Exclusion Question 3

Preview & Test INVOKE

Copy of Caregiver EOL Survey

3. Have you experienced a partnership with The Grand healthcare system in Pawling New York or received hospice service through The Grand Healthcare System in Pawling New York? (Exclusion) ⌵

Yes

No

50%


Prev Next

### Exclusion Question 4



Preview & Test INVITE

### Copy of Caregiver EOL Survey

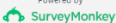
4. Prior to providing care at end-of-life, did you have clinical healthcare background or experience? (Exclusion) 

Yes

No

67%

Prev Next

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## Appendix D: Participants Thank You Exclusion Letter

Dear Participant,

I just wanted to take a moment to express my sincere gratitude for your interest in participating in my research study. I greatly appreciate your willingness to contribute to my project. The university has strict ethical policies regarding specific inclusion criteria, which we must adhere to in order to maintain the integrity of the study. Please know that your interest and willingness to support my research do not go unnoticed, and I am truly grateful for your enthusiasm.

Thank you once again for your understanding and support. If you have any questions or would like to discuss this further, please do not hesitate to reach out to me.

Sincere regards,

Brandan Margaret Rose

Doctoral Candidate

Walden University

## Appendix E: Participants Thank You Follow-Up Letter

Dear Participant,

I want to express my sincere gratitude for your participation in the research study titled Effect of Education and Policy on Informal Caregivers' Experience of Grief with End-of-Life Care. Your willingness to share your thoughts and experiences has been invaluable to the success of this critical study. Your responses have provided a wealth of information that will inform organizations and stakeholders and advance our understanding of the effect of education and policy on informal caregivers' experience of grief with end-of-life care. Your participation has been instrumental in making this research study possible, and I am grateful for your time and effort.

If you have any questions or concerns regarding the study, please do not hesitate to contact me. I will be more than happy to assist you in any way I can.

Once again, thank you very much for your valuable contribution to this research study.

I appreciate your participation.

With warm regards,

Brandan Margaret Rose

Doctoral Candidate

Walden University