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Talking About Death: Exploration of the Impact of Death Communication Norms on End-of-Life Caregivers

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Talking About Death:
Exploration of the Impact of Death Communication Norms on End-of-Life Caregivers

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The signatories of the committee below indicate that they have read and approved the thesis of Maureen Hampton McKenzie in partial fulfillment of the requirements for the degree of Master of Social Work.

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Dedication

This work is dedicated to my parents who taught me to talk about death. And to those who I loved and died in my life: my grandmothers, Jean and Mary, Aunt Mary, Uncle John, Aunt Barb, Conrad, Johnny, Matthew, and Ben. They taught how talking about death is important to my own grief and understanding my own mortality.

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Abstract

This study seeks to understand the experience of end-of-life caregivers and how their subscribed communication norms regarding death impacted their caregiving experience and preparedness to make decisions on their person's behalf. Eight participants were recruited from a Midwestern support group facility with a population of nearly 8,000 members that include cancer and grief support members. Criteria required adult participants that were less than 10 years out from their caregiving experience. Phenomenological research methods were used capturing eight opened ended interviews about participants death communication history, caregiving experience, and reflection on current death communication norms. Thematic analysis was utilized to assess common themes amongst the participants. Themes included patterns of communication norms, previous caregiving experience and longer term caregiving as protective factors, and collaborative communication about caregiving was a protective factor for reassurance in decision making. The themes support further research and implications for future practice for earlier interventions to establish end-of-life care directives, education about end-of-life and care needs, and postventions for caregivers.

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Chapter 1: Introduction

Talking about death can be anxiety and dread provoking (Bachner, O'Rourke, & Carmel, 2011; Carmack & DeGroot, 2016; Carmack & DeGroot, 2020; Scheinfeld & Lake, 2021; Shearman, et al., 2021). Western culture based social norms avoid the subject of death (Banner, et al., 2019; Carmack & DeGroot 2020; Freeman & Elton, 2020; Omori et al., 2022; Scheinfeld & Lake, 2021; Suntai, Noh & Won, 2022). However, research shows that openly discussing death, clarifying end-of-life (EOL) wishes, and discussing Advanced Care Planning (ACP) are protective measures from these negative experiences (Banner, et al., 2019; Keeley & Baldwin, 2012; Miles & Corr, 2017; Strupp, et al., 2021). Social or familial death communication practices are a pivotal component to facilitate this type of communication before or during EOL. While death and loss are not preventable, there are measures that can be taken to improve the dignity and quality of the EOL experience for both patient and caregivers (Banner, et al., 2019; Keeley & Baldwin, 2012; Miles & Corr, 2017; Strupp, et al., 2021). A gap in research exists as to the impact of social norms when communicating about death before and during EOL regarding frequency and language used as a potential protective measure for patient and caregiver.

Researcher Bio

I am employed at a Michigan based support group facility as part of the program staff where I facilitate support groups for those on a grief or cancer journey. During my coursework for my master in social work degree, I have focused my research on EOL care, needs, treatments, and social justice for this stage of life. I was raised in a home where death was allowed to be openly discussed and I, anecdotally, experienced the avoidant social norms discussing death when I would attempt to have these discussions with peers and people outside my family unit.

The information I have gained professionally and as a student has affected my consideration for a need to gain more valid information on the impact of end-of-life discussions on caregivers and their person's death. One of the primary areas of influence has been from the members of sharing their stories as caregivers before and after their person died. I recognize a bias in my own life of finding comfort and solace in my own end-of-life discussions. I have an advanced directive and have been thankful for times I was able to sit bedside with a loved one during their EOL. While I recognize the existential distress these discussions can cause in myself and others, my experiences discussing death has influenced a feeling of comfort with death and a desire to discover if this could be effective for others.

Purpose

The purpose of this phenomenological research is to examine the lived experience of caregivers with EOL decision making responsibilities. This study seeks to understand the perspectives of these caregivers with regards to how their personal communication and language regarding death and their subscribed norms impacted their EOL caregiving experience and preparedness for making decisions on their person's behalf.

Scope

The scope was limited to residents of the Midwestern United States due to accessibility and seeking participants who reside in a predominately Western culture-based community. The population needed access to the internet and a computer in order to participate in virtual interviews or work with time limitations for in-person interviews within the support group facility for privacy and location neutrality. Participants were limited to consenting adults who were at least 18 at the time of their caregiving experience. Participants self-reported as holding the responsibility to make decisions on their person's behalf, if necessary, without requirements of what decisions were or were not made while acting in this role. Eight interviews were used in the study limiting the scope of population sampling due to time restraints on study completion.

Research Question

How do the subscribed communications norms discussing death impact an end-of-life caregiver's ability to fulfill their role to advocate for their person's end-of-life wishes?

The aim of this study is to:

- Explore how social practices of discussing death prepare people to participate in their person's EOL decision making.
- Understand how prior knowledge of a person's wishes for EOL care enabled the caregiver to advocate for their person.

Significance

Caregivers are in a unique position to assist their person through the EOL process. For many people the avoidance of discussing death would potentially impact a person's understanding of EOL care for the caregiver and their person. This lack of knowledge and avoidance of discussion would impact their ability to make decisions respecting their cultural beliefs, personalized quality of death, and could result in potential harm and standardized medicalization of their death experience. Research shows that as the elderly population grows, there will be an impending need to have caregivers who have clearer knowledge and understanding of their person's wishes to advocate for a personal quality of death experience (Scheinfeld & Lake, 2021).

Developing an understanding of how subscribed communication norms discussing death impact the caregiver's ability to advocate for their person would help identify existing barriers as well as protective factors to normalizing discussions about death. Moreover, findings of this study will contribute to closing a current gap in the literature by illustrating the potential benefits of normalizing death discussions. Understanding the caregiver's experience and supports that are needed can minimize the need for standardized medicalization of care in EOL.

The support group facility utilized for sampling has a program in their local schools that facilitates discussions and coping skill development around grief, cancer, and other difficult experiences in 5th grade classroom programs as well as middle school and high school support groups. Findings of this research study can be important in providing supporting evidence for the existence and expansion of programs such as this one which advocate for change in cultural norms with early interventions of discussion, coping skills, and education to facilitate personal and peer support communication skills.

Definitions

- Health care advocate/proxy is a person or persons who act as an advocate for a person's personal wishes in medical care. This can be a professional such as a social worker or a layperson, family, or friend, who is designated by the person to advocate for them. This person would often be an assistive mediator in decision making between their person and their medical team and a primary decision maker when their person is unable to make decisions for themselves.
- End-of-life (EOL) is a time where death is medically considered imminent. The timeframe would be indicated by a terminal or no longer considered curable condition or illness and can reasonably be expected to a cause a person's death within a 6 month period.
- Advanced care planning (ACP) is the process of planning for a person's death including the care options, preferences and the assigning of a health care proxy or advocate usually

through assignment of medical power of attorney.

- Advanced directive (AD) is a document used to provide directives in the case of a person being incapacitated and unable to make decisions for themselves. The Michigan advanced directive documents include decisions for resuscitation, bodily wholeness (decisions to remove a part of the body or work to keep it intact), and directives for life quality into imminent death to assist with further unforeseen decisions. This document includes an option to designate a medical power of attorney and provide directives for bodily arrangements after death. This document is often requested and held by a person's primary care physician or in their medical chart to put into action when it becomes necessary. This document is not always immediately accessible or utilized if not in possession of the health care team caring for the person.
- Living will (LW) is a document that can be changed by the person enacting it to designate decision making upon their incapacitation or death. This document would require access and legal transfer to health care proxy or medical power of attorney at time of need.
- Power of attorney (POA) is a legal designation of a person or persons who are able to make decisions on their person's behalf if they are incapacitated. Medical power of attorney requires language specific to medical decision making in the document and is often included in advanced directive forms. Power of attorney for medical decision making in Michigan requires letters from two separate physicians indicating that the person is incapacitated.
- Western culture is defined as English speaking cultures that were founded by European colonization and are strongly influenced by Christianity. These geographic areas would

include North America, particularly the United States and Canada, and Oceania, particularly New Zealand and Australia.

For the purpose of this study the word caregiver stands to encompass a non-professional person, a family member or friend, who is acting as health care proxy/advocate as indicated in an AD, LW, POA, or direct acknowledgement with health care team. The word caregiver was used so as not to fall exclusively under one or the other specific guidelines of legal title and often can be a designation made specifically with a health care team at time of terminal status or immediately before a potentially incapacitating procedure rather than preplanning process such as ACP. This broader inclusion allowed for a sampling that would include those that were designated decision makers for a person but without legal paperwork or narrowing of a specific type of designation as the majority of people go into their EOL without these legal designations completed (Bischoff er al., 2013; Hong & Kim, 2022). The deceased is indicated as “their person” so as not to assume relationship or identities of those involved and subscribes to the language norms of the Michigan support group facility utilized for sampling.

Chapter 2: Literature Review

In Elisabeth Kübler-Ross's seminal work On Death and Dying, she argues that communication between patients and family members about EOL wishes is important to the personalized quality of death and caregiver experience and is often overlooked by the cultural focus on her Five Stages Model introduced in the book (Corr, 2021; Kübler-Ross, 1969; Scheinfeld & Lake, 2021). Much of research has agreed with Kübler-Ross's assessment that in Western cultures and more specifically the United States where Kübler-Ross's study was based, there is a tendency to avoid the topic of death that may go as far as denying the reality of death even when a loved one has entered the EOL stage (Banner, et al., 2019; Carmack & DeGroot 2020; Freeman & Elton, 2020; Omori et al., 2022; Scheinfeld & Lake, 2021; Suntai, Noh & Won, 2022). A knowledgeable caregiver paired with ACP can help facilitate the best quality of death for EOL care (Higel, 2019; McAfee et al., 2019; Omori, et al., 2022).

While most of the population acknowledges the need for death discussions the inverse is true in actualizing these communications even within families or community members whether due to general avoidance of the subject, lack of education on EOL, or lack of resources to facilitate EOL discussions (Kavanaugh, Noh, & Zhang, 2016; McAfee, et al., 2019; Shearman, et al., 2021; Strupp, et al., 2021). Research supports the need for seeking cultural understanding of community level death communication and avoidance of ACP to improve preparedness for EOL (Banner, et al., 2019).

Most research focuses on ACP when evaluating EOL communication, which can include discussions about Advanced directives (AD), Living Wills (LW), Power of Attorney (POA) or assignment of a healthcare advocate or proxy (Bischoff et al., 2013; Gerst & Burr, 2008; Hong & Kim, 2022; Kavanaugh, Noh, & Zhang, 2016; McAfee et al., 2019; Shearman, et al., 2021;

Strupp, et al., 2021). For purposes of this paper advocate or proxy will be referred to as caregiver from now on. A 1990 supreme court ruling that enacted the Patient Self Determination Act (PSDA) required health providers to ask or seek AD before taking life sustaining measures, but circumstances do not always allow for this step and a caregiver is meant to be an asset in making sure that these directives and any other cultural or personalized wishes are met (Crane & Wittink, 2005).

Focus on ACP is limited considering studies show that 70-85% people in the US across all demographics do not complete any formal directives for their EOL care and these percentages range higher when exclusively looking at minoritized populations (Bischoff er al., 2013; Hong & Kim, 2022). This poses limitations on the available data about current ACP processes. Research finds the ACP and death communication avoidance are related in patient and caregiver lack of preparedness in EOL (Kirchhoff et al., 2012). Further hinderance of completion of ACP include distrust of the health care system by minoritized communities as well as medical and social systems that create higher likelihood of resources for heteronormative, white, higher educated, couples (de Vries et al., 2022; Hong & Kim, 2022; Suntai, Noh, & Won, 2022). Minoritized communities would require further supports for caregiver knowledge to help achieve quality of EOL as lack of ACP often results in lower quality of EOL (de Vries, et al., 2022; Gerst & Burr, 2008; Hong & Kim, 2022, McAfee, et al. 2019; Suntai, Noh, & Won, 2022). Though death avoidance and indirect language around death is motivated to protect the living and healthy, the results can be delayed transitions to palliative and hospice care and higher rates of death in hospitals as well as undue treatment and pain in EOL (Bischoff, et al., 2013; Freeman & Elton 2021; Gerst & Burr, 2022; Omori, et al., 2022).

One of the problems with relying solely on ACP for patient's wishes is that the language is vague and cannot possibly account for all scenarios that arise in EOL (Crane & Wittink, 2005; Higel, 2019; Kirchhoff, et al., 2012). A knowledgeable caregiver paired with ACP can help facilitate the best quality of death for EOL care (Higel, 2019). Research acknowledges the dangers of a caregiver's personal bias impacting EOL quality of care, but the gap in research does not acknowledge the potential impact on this bias if social norms of discussing death previous to EOL would have assisted in understanding the EOL patient's wishes more thoroughly (Johnson, et al, 2021). Death avoidance behavior acts as a form shielding the living from the dying experience that holds a mirror to their own mortality but overtime this act of protection further medicalizes and puts EOL in the hands of medical professionals who are not as equipped with broad cultural competency and opportunities for robust communication with patients to personalize care (Bachner, O'Rourke, & Carmel, 2011; Lowrie et al., 2018; Scheinfeld & Lake, 2021).

While there are studies that have evaluated the family dynamic and motivators in discussing death and EOL there is a gap in evaluating the mechanics of language and frequency in these discussions (Freeman & Elton, 2021; Kavanaugh, Noh, & Zhang, 2016; Keeley & Baldwin, 2012; Khodyakov & Carr, 2009; Scheinfeld & Lake, 2021). Similar studies related to discussions about death tend to focus on discussions once EOL has begun and focus on ACP and health care team discussions (Bachner, O'Rourke, & Carmel, 2011; Crane & Wittink, 2008; Generous & Keeley, 2022; Mukherjee, 2019). Family relationships and dynamics between siblings (Khodyakov & Carr, 2009) and between parent and child (Freeman & Elton, 2020; Kavanaugh, Noh, & Zhang, 2016; Scheinfeld & Lake, 2021) can be dramatically impacted in EOL due to role changes, responsibility expectation, lack of ACP or disagreement of ACP, and the hardship of accepting the loss of a loved one. Early conversations about death with children often catalyzed by loss or impending death are often avoided as a protective measure, though these conversations have been found to help them make sense of the death of a loved one and provides opportunities for meaning making and a sense of security (Freeman & Elton, 2021; Keeley & Baldwin, 2012; Strupp, et al., 2021).

Death acceptance in EOL is an important component to lower distress and improving the experience in EOL of both the patient and their caregivers (Bachner, O'Rourke, and Carmel, 2011). For a health care team to be able to provide quality care that is person-centered in EOL it is necessary to be able to gain understanding of the patient's EOL wishes from the patient and their family (Omori et al., 2022). Health care providers have a role in helping patients and family understand the transition to EOL palliative care and may have to use emotional leverage (Mukherjee &Thomas, 2019) but can be limiting as even in the medical field the definition of EOL is not clear cut and constitutes a greying of the boundary between medical care and personal preference (Lowrie, et al, 2018). EOL requires biopsychosocial interventions beyond medical models requiring multidimensional teams including family or friend caregivers to achieve holistic and quality care (Pentaris & Thomas, 2020; Peres, 2016)

A 2022 study reported 60% of participants having informal discussions about EOL but was limited in not addressing frequency and language norms in these discussions (Hong & Kim, 2022). Researchers Carmack and DeGroot developed a research tool in 2016 called CADS (Communication Apprehension about Death Scale) that compiled data of previous research since Kübler-Ross's work to create an analysis system to understand death anxiety and apprehension of individuals and capture the existential experience of death communication in Western culture. This tool was limited to measures of anxiety and general apprehension rather than the language and frequency impact of these measures. Initial research utilizing this tool found that younger people though less apprehensive have higher anxiety when talking about death and the reverse is true of older adults (Carmack & DeGroot, 2016). A 2020 study by Carmack and DeGroot utilizing this tool data found that death discussion apprehension does create a roadblock in EOL decision making for both patients and caregivers. Physicians support discussing EOL before it is being experienced (Crane & Wittink, 2005) but there is a gap in research as to the impact of overcoming apprehension and engaging in more and earlier discussions about death on EOL experience.

One of the main points of Kübler-Ross's 1969 work was learning from the dying. Research shows that open discussions with the dying can teach us about mean making, life appreciation including connections with others, spirituality not exclusive to religion, and social solidarity to name a few, but these lessons remain with the dying when death avoidance prevents communication (Drillaud, et al., 2022; Generous & Keeley, 2022; Hayden, et al., 2022; Keeley & Baldwin, 2012). The existential distress of EOL and avoidance through false hopes and not engaging in open conversation with the patient was found to not only impact the patient experience in EOL but that of the caregiver as well (Gerst & Burr, 2022).

Current movements online through designated online applications, social media, and physical spaces such as Death Cafes are harkening a movement towards social supports of open communication about death, EOL, and grief (Gibson, et al., 2020; Miles & Corr, 2017; Miller-Lewis, et al., 2020; Moore, et al. 2019). While these intentional spaces may facilitate death conversations, there is still a gap in research of outcomes of these potential changes in communication social norms about death (Miles & Corr, 2017; Miller-Lewis, et al., 2020). Research does find that openness to communication, education on EOL processes, and clarity of wishes would be protective measures to death communication engagement (Shearman, et al., 2021) which could include more ACP completion.

Chapter 3: Methodology

This phenomenological study posed the question of how do the subscribed communication norms discussing death impact an end-of-life caregiver's ability to fulfill their role to advocate for their person's end-of-life wishes? The aim of the study was two-fold:

- **To explore how social practices of discussing death prepare people to participate in their person's EOL decision making.**
- **Understand how prior knowledge of a person's wishes for EOL care enabled the caregiver to advocate for their person.**

Research Design

This research study used an exploratory, phenomenological design. Phenomenological research asks for an in-depth exploration of a lived experience of a specific phenomenon (Creswell & Poth, 2018). The phenomenon at issue is the experience of a person's communication norms about death and their effect on the role of being an EOL caregiver. The group from which the data will be collected will have criteria that determines that they have the lived experience of the phenomenon. It is the common themes from the different participants' experiences that will create the understanding of the essence of the phenomenon rather than the explanation and analyses (Creswell & Poth, 2018). The intent is to describe this essence and develop philosophical understanding.

There is limited research on how death communication norms of EOL caregivers impact the EOL experience. Keeping to phenomenological methods the study utilized semi-structured interview guides to conduct interviews with eight persons who have acted as an EOL caregiver in the past ten years. EOL caregivers are a non-professional person, a family member or friend, who is acting as health care proxy/advocate as indicated in an AD, LW, POA, or direct informal acknowledgement with health care team. This study had no requirements as to how actively they made decisions for their person, only the ability to understand and self-report as holding that role. These requirements serve the purpose to gain broad insight into the experience of making decisions including responsibilities of anticipation and potential need for decisions even if these decision-making needs did not come to fruition. Themes were noted through open coding of the data.

Participant Recruitment

Participants were recruited via convenience sampling using an email blast to all members and participants of a Michigan based support group facility. Flyers with the same information were posted in the facility (see Appendix A for sample of email). This method allowed and invited snowball recruitment. The email blasts were sent to approximately 8000 subscribers which includes all past, current, and potential clients of the facility.

At the same time support group facilitators, all of whom are master level social workers, acted as key informants and more directly approached members they assessed as meeting the criteria for the study including past and current members. These candidates were presented with the flyer and information provided on the flyer only. Clients of the facility were also able to suggest the study to people who met the criteria outside of the group support facility allowing for snowballing recruitment. Membership of a support group was not required or verified with any of the participants.

Permission was requested for the researcher to reach out to the candidate for further questions and participation arrangements as well as providing the researcher's contact information included on the flyer for participants who preferred to initiate contact. Verbal verification of participants meeting research criteria was confirmed upon initial contact before proceeding any further with participation. Scheduling was based on availability with in-person being more limited due to hours of operation in the facility which was utilized as a neutral location for conducting the interviews. Virtual interviews were not limited by operation hours as my home had private accommodations to conduct a virtual interview with candidates outside the facility hours.

Sampling

Convenience sampling was utilized for recruitment. Participants were selected based on availability and willingness to take part as long as they met the criteria for participation. Convenience sampling is appropriate because of time limitations to complete this study. Exclusion criteria was only applied in cases of volunteers not meeting the inclusion criteria or volunteering once the data analysis process began.

The inclusion criteria for participation consist of:

- Designated decision maker in the last 10 years for a friend or family member's end-of-life.
- Designation of role as caregiving decision maker can be formal or informal and no requirements as to whether a decision was made on their person's behalf.
- Must be a consenting adult, over the age of 18 since the time of caregiving experience.
- Report as cognitively, physically, and emotionally equipped to discuss details of this experience discussing death and end-of-life caregiving.
- Able to participate in an hour long interview.

Sampling was limited to participants that were less than 10 years from their caregiving experience to keep consistency in accepted and expected medical interventions in end-of-life care. This also was used as a timeline to have participants that who retained more accurate memory of their experience without limiting the studies likelihood of finding participants due to the sensitive and socially avoidant nature of the topic.

Limited demographic information was taken in the study due to the limitations of what was being assessed. Age was included in the data due to potential for time and experience being impactful on the participants communication norms. Gender identity was used as part of the data collection to respect the preferred pronouns and gender identities when writing the findings of the research but was not used beyond this. No other demographic information was taken in order to keep the data and findings focused on subscribed norms rather than any specific racial, cultural, or socioeconomic comparisons.

Research Ethics

This study was approved by the Grand Valley State University (GVSU) Office of Research Compliance and Integrity (ORCI)/ Institutional Review Board (IRB). The approved study is under protocol number: 23-164-H.

All participants were provided with the study's consent form [Appendix B] to review and ask questions about immediately before participating in the interviews. Informed consent was emphasized by providing clarifications on the interview process and the right of the participant to discontinue participation at any point. Upon completion of an interview, all data collected was immediately transferred and stored on an encrypted external hard drive to protect confidentiality.

Due to the sensitive nature of the materials that were discussed there was some risk of emotional discomfort, though criteria requested for participants to report cognitive and emotional stability, the ability to withdraw consent and discontinue participation was allowed at any point in the data collection process for any reason. All participants volunteered to participate. Direct recruitment as key informants within the support groups and past members were only conducted by group facilitators. Key informants limited their participation to providing the same information that was provided on recruitment flyers to make the candidate aware of the study.

If a person from one of my support groups decided to participate, no discussion within the support group was used and the participant was asked to tell their story as though I knew nothing about their grief experience. This was not difficult as many members tend to be limited in what they share within support groups due to the shared space and time limitations often resulting in sharing fragments of their experience with their grief. No history, notes, or profiles of members who participate were used or referenced before or during research collection and analysis. I was responsible for not treating any participants differently due to their participation and did not discuss or confirm that any individual participated. Though support group information is discussed amongst the facilitators, information provided in interviews was not and will not be included in any of these discussions to mitigate any potential impact on facilitator-member relationships or experience within the support groups and to maintain the confidentiality of the information chosen to include in their sharing for this study.

Data Collection

The data for this study was collected using an interview process. Interviews took place from February 16 to March 8, 2023. Participants were recruited using an email blast sent out to approximately 8,000 active and non-active members of a support group facility. Flyers were printed and posted in the support group facility. Ten potential participants volunteered for the study, of these, eight were interviewed and two were excluded. Exclusions were made because one did not meet inclusion criteria and the other volunteered after analysis had already begun.

The eight participants that did meet the inclusion criteria were given consent forms once inclusion criteria were confirmed by the participant. Consent forms [Appendix B] were emailed to allow time for the participants to review. Participants were all given the option to have the interview conducted in person or virtually. Of the eight participants three participated in the interviews in-person and five participated virtually. All the interviews, virtual and in-person, were recorded via zoom capturing video and audio.

Virtual interviews were conducted from a private space and the participants were asked to be in a quiet and private space on their end. Because the information being collected was their private information there were no further requirements of privacy on the participants choice of location when participating virtually. As the researcher, I made sure that I was in a space where sound would not be overheard, and a door could be securely closed to prevent disruptions. Recording was set to capture the in-camera view of the participants to see gestures and other non-verbal communication to imply additional meaning to the data collected. All participants framed themselves from the chest up and clear image of their face and movements with no background effects or blurring. All virtual participants already set themselves up for the interview in this manner and so there was no need for intervention beyond if a participant stepped out of frame for a moment to get a tissue or if there was a momentary connection issue. In these moments the conducting of the interview would be paused until the participant was back on screen and speaking again. On two occasions the recording was paused due to more severe zoom interruptions and the need to move to another room and one where there was a need to step away to grab a box of tissues, both occasions were during in person interviews. The same method of framing was used to record the in-person interviews and as participants were framed to capture the same amount of the participant from the shoulders up. Notes of nonverbals were not noted during the interview process and reserved for the recording analysis. No notes were taken during the interviews and reserved for review other than noting that a pause or interruption occurred. The choice to use recordings and transcripts rather than notes during the interviews was to make sure that each participant's whole experience was captured and not filtered through any potential implicit bias during the note taking process as to what was "noteworthy". Recordings and transcripts allowed for multiple reviews and an analysis process that would make sure to utilize all the data of the participants' interviews when creating findings and conclusions.

At the beginning of the interview all participants were given an opportunity before recording began to ask any questions in general as well as about the consent form they were given. All participants had no questions about the interview. The same review of consent, withdrawal, and structure of the interview were provided to all participants. Information for structure of the interview included that the interview was guided and that they should share their story from their perspective and if additional information is needed, I will ask further questions and I would only ask questions when needed or when transitioning to a new section of the interview. For all I made sure to share: "This is your story and experience and I want you to share what feels important and relevant to you." These methods and information were provided to facilitate a freer flow of information and help participants focus on providing their story rather than working to answer my questions. This was important for maintaining the capturing of their lived experience that is essential to phenomenological research.

Participants were informed that there are three sections of the interview that I would first ask about their history discussing death in their lifetime, the next would ask about their caregiving and decision-making experience, and finally their reflections back on their experiences. I also informed all participants that they would have a chance at the end of the interview to share anything important that they felt was not captured in the recording.

I reviewed with participants that for confidentiality I would be capturing a recording of their consent at the beginning of the interview and assign them a number to identify them. Numbers assigned were in chronological order of interviews conducted starting with 001 to 008. All participants were asked if they would like to use a pseudonym for their person to replace any use of their name during the de-identification process. Two participants requested pseudonyms for their person and the remainder asked for them to randomly be assigned during the deidentification process. Any other names mentioned in the interviews were assigned random pseudonyms. Pseudonyms were chosen based on simple ubiquitous names in Western culture such as Jane, John, or Mary.

Once recording was started, I recorded consent by asking, “Are you consenting to the audio and video recording of this interview to be used as data for this study?” and participants provided a yes or no answer. All eight participants gave an answer affirming their consent to proceed and thus we proceeded with the interview with the aid of an interview guide [Appendix C]. The interviews were directed by the participants and the experiences and stories they wanted to share. The interview guide was used as a tool to facilitate the flow of the conversation and to elicit additional information as needed. When a participant asked for clarification of a question it was reworded or a definition of a word would be offered. When clarification was needed from the interviewee, a paraphrased summary of what was shared was stated and asked if I was understanding correctly.

When the interview was complete, as noted in the beginning of the interview, I asked the participants if they felt there was anything they wanted to freely add to what they shared or felt was important to note. All but two participants chose to provide additional information at this point in the interview. All interviews stayed under the 60-minute mark other than the participant who spoke of two caregiving experiences and the time extension was noted and anticipated by the participant and me prior to the interview.

As each interview was completed, they were sent to an IRB approved transcription service called Rev.com to have verbatim transcriptions completed. None of the transcripts were reviewed until all the interviews were completed. Once the transcription review process began this was the point where further participation was excluded and steps towards analysis began. To begin prepping the data for analysis, each interview was reviewed to verify verbatim capturing of the participants words. Verbatim would define that all words were captured. There were only two points in the data where neither I nor the transcriber were able to hear what the participant was saying but were never more than 1 or 2 words. Part of the review process included non-verbal communication noted in parentheses ( ) and used to maintain intended meaning once the analysis process began and left in quotes used in findings when they were impactful to tone.

Data Analysis

Thematic analysis was utilized for this data. When grasping the phenomenological experience of the participants and gaining a perspective and unique insight into their lived experience it is important to utilize an analysis process that allows for this experience to come through. Thematic analysis is designed to utilize the data provided to discover patterns within the information shared by the participants to describe in detail their experiences and from these patterns discover any relationship of the data provided to the question posed (Braun & Clark, 2006). The specific steps of thematic analysis for these interviews began once all the interviews were complete. All of these codes were cross referenced and clustered to build textural descriptions of how the participants experienced their communication history and it’s impacts on their caregiving role; these descriptions were used to create a composite and develop the essence of the lived experience (Creswell & Poth, 2018). These composites were interpreted into themes drawn from patterns and saturation across the interviews.

The first step of analysis started with what would be called open coding. These codes refer to creating a simple two to three word synopsis of sections of information provided by the participants. Each interview was reviewed, and sections were copied and pasted into an excel spreadsheet. The “Open Coding” section of this spreadsheet included a column for the participant identifying number, the code, and the copied text from the transcript. The participant identification numbers were used to help confirm saturation of data between the different interviews when interpreting the final themes. Times where two to three words were not enough to describe a section, they could be duplicated to capture any additional important meaning they may have. An example of one of these duplications would be if a participant in the same couple sentences discussed their faith and a previous caregiving experience and this would be given a label for each of those.

Once open coding was complete there were 246 unique codes compiled in the excel spreadsheet from the data and with duplications there were 271. From these codes a sorting process was used in reviewing the codes to group them together based on similarities of the codes only. There were 18 bundles created for the codes. These bundles were all captured in individual tabs in the excel spreadsheet with the original three columns of data from the open coding process: participant ID, code, and verbatim quote. Each section of bundles was reviewed based on number of participants and summarized to gain a broad understanding of what was shared within the quotes including notes based on the broader experiences of the contributing participants in each section for context.

When reviewing the summaries together any connections between the summaries were assessed with consideration for how many participants were included in the bundles. From these summaries and notes of saturation of data across the participant interviews, patterns were found in what was being shared. These patterns became the themes within the findings to inform further research and implications for future practice and supported in the findings with direct quotes from participants. The only editing of these sections was removal of redundant or off topic sharing to the support of the theme and replaced with an ellipse (…) to clarify support of the theme. Interjections of active listening by myself as the interviewer were also removed as it was not considered impactful on the information being shared.

When analyzing the data protective factors were found within the themes. Protective factors are components of the experience that participants noted as being positively impactful and when cross referenced with other participants these emerged as positively impactful across multiple participant experiences. Data saturation was considered in cases where at least five or more participants provided information that supported themes and there was disambiguous support of the theme within the coded quotes.

TABLE: Steps of Thematic Analysis

Steps of Analysis Process	**Examples**
STEP 1: OPEN CODING: 2-3 word synopsis of participant verbatim transcript *271 unique codes*	Codes: EOL medical team; transition to EOL; previous death discussion; after death discussion; Person's death; imminent death discussion
STEP 2: CODE BUNDLING: bundling similar codes based on codes and not quotes 18 bundles	"previous death discussion", "after death discussion" were two codes of 58 bundled together under the label "Death Communication"
STEP 3: THEME DEVELOPMENT: summaries of bundles were written based on quotes captured. These were reviewed together finding link of themes between bundles and identifying themes.	The bundle "Death Communication" included patterns of discussing death only once a death has occurred, behaviors of avoidance, attempts at

	conversation, and reflections on whether they discussed death or not.
STEP 4: THEMES: data saturation to develop themes were based on patterns of data and number of contributing participants that were quoted supporting the theme *3 themes*	"Death Communication" as a bundle included supporting quotes from all participants and related to bundles summaries labeled "Caregiving", "Death Experience", and "EOL", all of which supported the first theme on "Patterns of Communication".

Chapter 4: Findings

The primary theme that arose from the data was the pattern of communication norms regarding death and EOL care. Death communication was stimulated by a death occurring in participant's lives as well as of their person's imminent death. EOL care discussions focused on their person's care, directives, and wishes during their caregiving experiences. These patterns associated communication about death with grief and EOL care with caregiving.

A secondary theme was how previous caregiving and longer-term caregiving provided protective factors for the caregiving process. These included a higher likelihood of going into EOL care with ACP, AD, or LW already completed as well as a clear understanding and assurance in what their person wanted for their EOL. This experience did not change the avoidance of death communication in the caregiving experience.

A final theme was the protective measures of collaborative communication in the caregiving process. Collaboration occurred between caregivers and their families, their medical team, and or their person. This communication and collaboration provided reassurance of decision making and understanding of their person's EOL directives and care. Collaborative communication mirrored previous social norms where communication about death was minimal and kept within the family unit keeping the focus of the caregiving experience on their person's EOL and not discussing death until death was imminent or once their person had died.

Patterns of Communication

There was a noted distinction in communication experienced as EOL caregivers between EOL care discussions and death discussions. Participants' communication about death was stimulated by death. In their history they discussed death when a person died in their life whether with a brief acknowledgement or a full discussion.

During the actual caregiving experience the discussions of “death” were exclusive to their person’s EOL care, directives, and wishes. The distinction between death and EOL care as topics of discussion was clear between all participants. Their historical subscribed norms of death communication were also mirrored in their later communication. For those who experienced more avoidant social norms, they had to break from their familial norms to seek grief counseling.

All participants recalled speaking of death when an actual death occurred, but minimally if at all outside of that. One of the younger interviewees whose mother died spoke to this when she said, “I think for the most part in my family, our discussions about death were usually kind of spawned by a death of somebody that we knew. Typically, don’t try to think about it, I guess.” The experience of only discussing death when a death occurred was shared by older participants as well.

> I don’t remember ever talking about death unless it was probably a death of a pet or grandparent. I haven’t really experienced a lot of deaths, but as it being a topic of conversation at the dinner table, it was not.

One of the other older participants noted something unique to the older adult experience when he shared, “The older you get, the more people die. So you discuss death in your life more often.”

Each participant’s patterns of discussion mirrored their discussions in caregiving and their grief. For some who noted that death discussions did not feel uncomfortable or avoided directly but more so that it did not come up as a natural topic outside of when a death occurred relayed a higher likelihood of discussing death before their person died when death was imminent. In this example a participant who was caregiving for his fiancé and expressed being comfortable talking to her about anything still struggled with how to have this conversation with her.

> And it wasn't until really, the end that we got to talk about it. And I remember she's saying, she's like, "I wish we had talked about this sooner." I said, "Me too, but we're

> talking about it now." I think we just avoided any conversation that would make her think that she was going to die until it was clear and obvious.

Families that were more historically avoidant discussing death were found to have more difficulty with direct EOL discussion and assurance in their decisions during the caregiving experience. One family was very clearly noted by the participant avoidant of discussing death even with opportunities from her mother's career that required her to work in funeral homes. The participant, who is the daughter of the family, and her family were caregivers as a team, but direct discussions of death remained an avoidant topic into their grief experience after the father of the family died.

> We're still a very hush hush family; you don't really talk about those kinds of things…I think both her and I can trauma bond on the things that we saw him go through that our siblings can't. But we really haven't talked about those things. I've told her, "Hey, maybe you should go to therapy for those things you saw, because that was horrible. And I also saw them." (chuckle) And I think she tells me more about those things. She'll make brief comments about, "Oh God, yeah, when dad was screaming out for his mom when he was in the middle of dying, that was horrible." And then I said, "Yep, I saw that too." But that's it. You just say that, and then we were like, "What do you want for lunch?" There's a lot of open the wound and then close it really quick.

Before the caregiving experience this same family was more likely to have discussions when the death was considered more traumatic though done in a manner that restricted the information provided, particularly to younger people. Though the caregiving experience was noted as "trauma bonding" the same restriction continued.

> My brother lost a good friend when I was maybe eight and he was maybe 10 or 11. And I think that's the most we ever really talked about it. It was a suicide situation, so there was a lot of keeping the kids out of it and just making sure they had no idea what really happened.

These two examples show how the patterns of the unsubscribed familial norms historically carried through into the caregiving experience.

One participant who provided a similar account of death experiences also noted, “There were no topics that were taboo in my family.” She noted in her interview that the shared caregiving of her mother and previous caregiving of her father was a bonding and supportive experience with her siblings and other family members as reflected in her history of death communication.

> It was all one and the same, kind of. When [boyfriend] died, oh, all of us, friends of his, got together every single minute. We were hanging out in one of our basements, and we were all together in our grief around that. In our community, we all just hugged each other and got together and talked about it. It wasn't anybody who stayed home and did their own thing around the grief. It was very, very open. Same with all my other family members, aunts and uncles who died, and when my cousin's parents died, and we all were there for each other.

Grief was a primary time of death communication which follows the pattern presented in the data. There was a suggestion by a participant that the experience caregiving was impactful in seeking opportunities to discuss death after their person died even if it required breaking from previous norms.

> I just think that, and I said this to so many people over the last 20 years, and now I lived it, that caregiving is the greatest mission you ever have in your lifetime to take care of someone you love who's dying. It leaves the biggest hole because not only do you love the person, but my life for that last three or four months, that is all I did… Now I know what it really was like, to help that person that you love go into the next world. It's a privilege, a real big privilege. Yeah. It was exhausting, too. It was.

This participant reported not discussing death with her person and minimal personal discussion of death in her life beyond, “conversation about how and why that happened, but nothing that got very deep. It was more the practicalities of it.” She did report seeking grief counseling to have the conversations about death that she wanted to share but did not want to force her husband to have with her if he was not willing to. For her, it takes two people to have a conversation and she wanted to prioritize his experience and wishes in his EOL over her desire to talk about it.

> I wasn't going to put my need to talk about anything first. This was about him. To me, this was about him. He was the one who was dying and I was the one, I had time to fix things for myself, but he needed to do this the way he wanted to do it.

Like this participant's experience, readiness for conversations about death did not always line up, no matter their personal historic norms, and prevented the conversation from happening at all. For some it was the caregiver who did not want to talk about their person's death.

> I think the biggest regret maybe a lot of people have is not really talking with that person about it. I think a lot of us were maybe scared to talk to him about it because you don't even want to think it's a possibility, let alone that person know that you also think it's a possibility.

For others it was their person who did not want to discuss death and whose historical norms were not captured as part of the data collection. One participant, who was caregiving for his fiancée, remembered having an awareness that his fiancée was going to die, though they did not talk about it because she was not ready to.

> But I don't think I really ever expected things to improve. And it was different in [my fiancée]'s eyes. She didn't accept that she was going to die. I think she thought about it, but it might have been the fact that I acted. In my head, I'm thinking she's going to die and it's going to be any day. But I never alluded to her that I was thinking that way. It was, "You are going to get better." And that's something I struggle with a lot. But I think, at a certain point, she was diagnosed in the middle of July and by the end of October I started to be like, "Okay, it's not getting better, it's going to be sooner rather than later." And soon enough the doctors are like, "Well, you have less than a year." And I'm sitting here thinking, "We haven't talked about anything. The word death hasn't even come up." She wanted things to be, I think, as normal as possible. She didn't really, I think, want to have those conversations at first. She wanted to get better and she was going to do anything, any treatment she could to live as long as she could.

Once they did talk about death towards the very end the primary focus was on him and not on her death directly.

> I remember, [my fiancée], one of her main things was when we did finally discuss it, she specifically made a point to say, "I need you to be okay." She said, not even I need, she said, "You're going to therapy," basically. And I remember the very next day after she died, right after the pickup trucks came, pick up the hospice bed and stuff, I'm sitting there on my computer looking at researching therapy offices and stuff like that. And I

> finally found one and I requested an appointment and they sent me the flyer like, "Why are you here?" And I'm like, "My dead fiancée told me I have to be."

This participant like many of the others found that seeking support after their person's death helpful and was a place where they processed and discussed death. For this particular case, he found that he could use those spaces to share about this part of his relationship that other people in his life would prefer he not talk about.

> I miss her more than literally anything in life, but no, I don't feel that I get to talk about [my fiancée], or at least her experience with death and the whole caregiving side of things. And it was such a big part of our relationship. I met people who are in their later in life and they've lost partners of decades. And [my fiancée] and I were together for six years and six months of that, she was dying.

During caregiving, the focus was on their person and their needs. After their person died, following the thematic pattern, they engaged in discussions about death. Many did not find receptive audiences without seeking professional resources and support groups provided peer connections.

> I'm in grief support group and I have a friend there that we talk about each other's spouses freely and the process and everything. It's a great help to be able to tell somebody who gets it to start with and then next, doesn't mind listening to you, doesn't run from it, doesn't hide, doesn't feel helpless type of that. That's nice.

While continuing the pattern of death being discussed once a person has died, the participants reported further need discussing their person's death. Their caregiving experience brought them to a place where they were no longer tolerant of avoidant social norms discussing death.

> I think it was actually after my mom's death and it was probably, I don't know, maybe a year and a half ago. It was actually, I think at least I recognized it in grief support group because other people were talking about their person had passed away and they were using this soften language. And I was like, "Yeah, my mom died in 2019. Period. Let's go." And I had never really recognized it before, but I remember at one point specifically about a year and a half ago, I got out of grief support and I really was processing the information and I felt like I just used very different language than everybody else did that time. And it made me sort of realize that maybe that was like, I don't want to say a switch flipped, but it was almost like, "Okay, I've come to terms with it. She's not passed away. She's dead." That's it. I don't know. I guess I just felt like I was confronting it more head

> on. But it was probably about a year and a half ago. Because you see a lot of people and a lot of the people that do struggle with death, it seems like they're just not accepting of it and not to obviously throw anybody else who is struggling with it under the bus. But it does kind of feel good and it's almost cathartic to be able to just say, "You know what, they are not passed away, they are dead." And it brings a certain amount of closure, at least for me, to be able to say that and not break down.

Another participant concurred with this and added some feelings about how death discussions should change.

> I think that maybe, as a society, we should figure out a way to bring it up in a way that's not so negative. I don't know. I don't a way to put that, but- I don't know. I think maybe, maybe, my dynamic with my dad makes it a little bit harder, a kid and a father. I think even if I had directly asked him, he might've tried to protect us and not been honest about how he was feeling like he was with my mom. But yeah, I don't know, maybe. I think maybe in the care taking role, it's a little bit easier to have that conversation solely because you're relying on someone else to keep you alive. And maybe there's that burden of information. Maybe you guys should talk about it because I'm keeping you alive. But I don't know, I don't know if there's a good way to make that conversation more comfortable or accessible.

The thematic patterns of communication made the participants’ changes in communication after their person’s death clearer to them. These patterns also highlight how avoidant social norms discussing death remained until their person’s death was imminent or their person died. Because all people involved in EOL care are bringing their own subscribed norms and history discussing death with them into the experience, prevalence of avoidant norms persisted in EOL care until the participants were able to seek care and options for discussing death during their grief.

Previous Experience

Those participants who had previous caregiver experience and or were long term caregivers for their people prior to them going into EOL care, noted more knowledge of their person’s directives and wishes for EOL as well as assurance in their decision making. These experiences acted as a protective factor impacting their EOL caregiving experience.

One participant who was a caregiver to her spouse, who had a long term illness also had experience caregiving earlier in life and reflected on how this changed the conversation.

> My grandmother was sick for a long time and then she died when I was 19. And then my mom was sick for about three years before she died. I guess maybe in both of those cases we also could see the writing on the wall. At a certain point it was like, "Well, they're not going to get better and we just got to figure out how we're going to get through it." Maybe that was kind of when we started just talking about it and being more open about it…And so it was easier for us to talk about it through the entire process.

When this participant was making decisions about her spouse's care, her years of caring for him was reflected in how they discussed and made plans for how to manage his care.

> [My husband] had had some back infection, and they never did diagnose it, so he couldn't walk very well for the last three or four years, and that's not what he died of. He died of kidney cancer, but this already had started the process of me being a caregiver for him because if we went anywhere, it took a lot of planning, thinking, this kind of thing, so that started it… We'd work together to figure out how am I going to pull him up. He would lay there because he was a doer and a thinker and a fixer until he'd think about, "Okay, we're going to call [neighbor's name] next door," and then he would figure that out, and then we'd put the plan in place.

Another participant who was a caregiver for her spouse for over 18 years and was a caregiver to her father before and mother after her husband's death, had a lot of experience with EOL caregiving and close encounters with it. She shared this about caring for her husband before he was in EOL care.

> Over the years, because he was on dialysis probably 18 years, we've had many mishaps, like one, we had it set up where we just watched TV as he'd do it and stuff. He says, hey, I'm getting light, and so I went over to look at the machine and I'm slipping and sliding and turned the light on and there's a huge pool of blood. The machine had opened, so every pump was pumping his blood onto the floor, and it's like, okay, react. Then that was, get him stable, call 911, open the door, put the dog away, get the right stuff, and stuff like that, and it was just like that.

She reflected on having an easy flow of conversation during her husband and mother's care and noted others in her family struggling with it who had not had the same caretaking experience.

> Now, if you want to talk about the conversation I had with both of those people, it was easy and flowed and we talked casually about it a lot. The interesting thing about this is

> my mom and I would have a fluid conversation, whereas my sister and brother were like, eh, couldn't handle it, and it was so odd, I think, but I don't have a problem talking to anybody about it.

Like other participants she was able to note ease and comfort after her previous experiences with caregiving.

For one participant who was a caregiver for his wife through life long chronic health issues, his knowledge of his wife's directives and wishes was on par with the others who had previous experience. The negative factor he experienced was the inability to grant some of her EOL wishes, primarily being able to bring her home.

> Even if you make the decision that your reason told you to make, your emotions, they still come after you. This is just another case of that. I had to do what I thought reasonably was right. And emotionally, it's still haunting me, always will. Everybody tells me I did the right thing. Maybe they're all just being kind, but actually they're all just being rational like I tried to be. Oddly enough, it doesn't help much… No. See, that's the problem; I made the rational decision. The emotion decision would have been to attempt home-hospice. I knew all along she wanted to be at home; that's what she told me. I just couldn't do it.

His clear awareness of her desire to die at home and his inability to bring her home made his decision making that much more difficult to manage. His relationship with her as a caregiver and understanding one another's wishes still allowed him to reflect on forgiveness from her in his grief. "But the only other thing I want to share is that I made some poor decisions, if I did, that I know that she forgives me. Because if it were for her, that's really important to me."

These previous caregiving experiences create practice and exposure to conversations necessary to have assurance in EOL decisions. These participants with caregiving histories had more knowledge and comfort in discussing and making decisions on their person's behalf even when collaboration to assist in decision making was limited.

Collaborative Communication

Communication during EOL care was essential for all the participants and facilitated knowing up to date directives, understanding care options, and opportunities for their person to express their wishes for their final days and care for their body after their death. For many of the participants collaboration with their person, family members, and the medical team were essential for making the timely and difficult decisions necessary in EOL care.

One participant's primary reassurance was directly making decisions with her spouse. She said, "We made every decision until he was unconscious together. That's who he was. He wanted to be involved in every decision in our lives, and we continued to do that, even to the fact when he was bedbound."

Many of the participants who were able to work together as families to care for and make decisions for and with their person would refer to each other as a team and would often delegate roles to help everyone do all they could to help. One participant whose family notably did not discuss death beyond acknowledging it when it happened came together caring for her father.

> It was really natural, surprisingly. I have my twin sister, and then I have an older brother, and then my mom. We also have an uncle who helped out quite a bit. My brother is really, really big, he's a big muscular guy, naturally his role was helping my dad move and get up to go to the bathroom and carrying him when we needed to. My mom was in charge of all the bills and the medical, talking to doctors. My sister's really organized; she took on organizing the medicine, making sure that we had the dates we needed to give him this, this and this all set up. And I became, I don't know, the voice of empathy. I was the one who would stay up with him at night and keep him entertained and make sure he was trying to enjoy his last few months.

This same family found support in decision making when a member of the medical team stepped in with some clarifying information. "He looked at me and he says, 'You don't want him to wake up…if he wakes up, he's going to be in hell.'" Stopping resuscitation was a decision that the family was struggling with but a decision that needed to be made right in that moment. The participant noted how difficult it was to hear what the doctor said, but how reassuring is was for making the decision to do so.

Another participant whose family was their primary collaborators spoke of how close this made her and her siblings after caring for their parents. “I’m so grateful for my siblings still. We’re still so tight and we will always have that because that’s what our parents taught us…None of us have any regrets about, what we were able to do, we did it.” This participant’s mother had a long battle with Alzheimer’s and because of this their father, who died before their mother, was able to contribute some collaborative communication on her care.

> One time, when I came home and he said we had to go see [my aunt] in the nursing home, which was my mom's sister. Then he said to me, "This would be a good place for your mom." That was his way of telling us that he liked what he saw there, and he probably knew that he was going to die before mom, and that we were going to take her. He was giving us his approval as that being a good place for her.

Later this participant expressed how difficult taking her mother to the nursing home was but the reassurance of family and modelling of care they experienced affirmed that they were doing the right thing.

These reassurances were noted to be protective factors for their decision making and facilitated conversations about EOL and the care that was needed. Collaboration was experienced with family, their person, and or the medical team but not all were always available or wanted. One participant who was caring for her father had some assistance from her family but her primary collaboration and reflection was with her father and the hospice nurse.

> I guess I was just very, very, very protective over his care and not getting too many people involved. I think it just comes from me being there from the very beginning when nobody else was. I was there from the beginning to the end. For someone to come in at the last minute and think that they know what's best for him, I think that's where I pushed back a little bit.

For her, family help felt like too many opinions without basis in her father's best interest and knowledge of his experience. She found support however in collaborative communication with her father's hospice nurse. Through this relationship, she was able to find the reassurance she needed.

> Oh, he was amazing. He was so great and the sweetest guy. It made me happy knowing that my dad was happy with him too. He was happy with his care for the most part, but he explained everything to me and explained the process and what's going to most likely happen. When this starts to happen, this is the next steps that you should do. When this happens, then this is what that means, and then you do this. He was very, very thorough in the whole end-of-life process. He was probably the most knowledgeable and who I would go to the most because he just had the experience too. I could text him. I could call him and I could call hospice any time for anything.

One participant who was a caregiver to her husband for almost two decades for renal disease had her communication cut off when he was admitted to the hospital with COVID during the pandemic after having a transplant. It was in isolation that he died, and she was only able to spend the last five hours with him due to COVID rules. When she finally did see him she expressed thanks and comfort in knowing what they wanted from previous discussions when they were able to collaborate on these decisions during the over 18 years of caregiving she provided.

> And I know I can't regret my decision because I know it was the right one, and that's what we wanted. Because the alternative probably would've been a trach, a nursing home, no quality of life if he survived kind of thing. So I was comfortable with my decision.

A participant who was caring for her mother expressed a very clear regard for the importance of her collaborative communication with her mother, her family members, and the professionals on the medical team.

> My mom made it very clear that she did not want to be kept alive artificially from the very beginning. And so we knew that it ultimately would come to that. We knew that at that point we had our decision made anyway. She ended up bedridden at home in hospice care. When we brought in the hospice folks, they took a look at all of her wishes and her advanced directive and her DNR and all of those documents, and they went over all of

> them with us to make sure that we were aware of what was going on. And then from there, they were able to take us through what medications to give her, when and when to call them in. We were able to have that conversation and that communication amongst ourselves. But we were also really fortunate to be able to talk it through with professionals in hospice, as well. I think that that was really beneficial, and I think that we were very lucky to have that opportunity to do that before it got to a point of making those decisions, so we were better equipped to do it.

Collaborative communication in EOL care impacted the caregivers being able to make decisions and feel reassured about them. The primary subject of these communications was care, directives, and wishes but conversations about their person’s death were compartmentalized away from this experience caregiving and reserved for grief.

Chapter 5: Discussion and Conclusions

The findings of this study are consistent with the previous research noting the avoidant social norms discussing death in participant history and during the caregiving experience (Banner, et al., 2019; Carmack & DeGroot 2020; Freeman & Elton, 2020; Omori et al., 2022; Scheinfeld & Lake, 2021; Suntai, Noh & Won, 2022). Discussions require two people being willing to communicate, so unless both people are willing and ready to discuss death, these discussions did not happen. Avoidant social norms act as an additional hurdle to the likelihood of both parties being willing to have these discussions at the same time. When a person died in the participants' lives and death was unavoidably present, discussions of death would occur. Any experiences with a death in their life created opportunities in their avoidant social norms to discuss death but was avoided otherwise. This pattern of avoidance until death was unavoidably present was true in their experience as an EOL caregiver.

In sharing their experiences, participants made a distinction between discussions about care during the EOL process and the actual discussions of death itself. The data was inconclusive as to the impact of maintained norms avoiding communication of death during the EOL process, beyond some participants expressing regret not discussing death with their person during care. However, because longer term care experience was found to be a protective factor, which allowed for more time and opportunity to discuss EOL care resulting in a higher likelihood of having ACP in place and have a clear understanding of their person's wishes and directives. These opportunities are not available and part of everyone's care and EOL experiences.

Previous research has found that ACP and a knowledgeable caregiver are important elements of providing quality of EOL care but ACP and knowledge of wishes are rare previous to EOL care (Banner, et al., 2019; Keeley & Baldwin, 2012; Miles & Corr, 2017; Strupp, et al., 2021).Current ACP introduction and education puts the burden on medical professionals and can result in only being introduced later in life and limiting allowance for the time and opportunity to make personal assessment on EOL care (Crane & Wittink, 2005). Early interventions would allow for all individuals to take time to consider their own, and their loved ones wishes and directives in EOL and would acknowledge that death is not limited to elderly populations. Moreover, it would allow for the conversations of care and death for those who may be caregivers and for all humans, as we all will one day be the person facing EOL and could help lower that hurdle of discussion that was found in this study.

The participants noted how important collaborative communication was for them during EOL care, which broached the subject of EOL though would mostly sidestep direct discussions of death until their person's death was imminent. As supported by research, discussing EOL care including directives and wishes was a protective factor, particularly when done in collaboration with support people and medical teams to create understanding, quality of EOL, and higher likelihood of completing ACP (Omori et al., 2022; Mukherjee &Thomas, 2019; Pentaris & Thomas, 2020; Peres, 2016).

Though there was a lack of saturation, participants emphasized other themes of note. One of these was religious reassurance of decision making. The primary point was the impact on the caregiver feeling comfort in the idea of their person dying even though these comforts were not communicated. A second component to this was that expectations for directives and wishes after their person's death occurred was not a task necessary to communicate due to rites and services being already laid out by their religious practices. Expectations for their person's remains would have required communication acknowledging their death and this was unnecessary because it was already known and decided based on these practices. Though this did not facilitate communication, it does acknowledge the comfort of having an idea of what to expect to be assistive to the EOL process. This also shows how subsets of the population based on religion may have valuable information on EOL practices and how they impact EOL, and like people who experienced longer term care experiences there is limited reach of these protective factors to those that practice these religions.

Another theme of note that was impactful but with unclear saturation of data was how close the participants felt with their person. While the amount of time they spent providing care to their person was found to be a protective factor, there was a lack of measure and clarity of the “closeness” of the relationship. The idea of “closeness” and implicit understanding of their person’s needs was noted by participants in particular those that were caregivers to a spouse. Rather than noting a protective measure it may point to risk factors for those going into EOL with a spouse. Two participants who were caregivers to their spouses directly acknowledged these concerns for themselves. Previous studies have investigated the impact of family dynamics on EOL care as well as the inverse of EOL care impacts on family dynamics but is limited on defining relationships beyond roles in the family (Freeman & Elton, 2021; Kavanaugh, Noh, & Zhang, 2016; Keeley & Baldwin, 2012; Khodyakov & Carr, 2009; Scheinfeld & Lake, 2021). There is already research on how our current ACP completion interventions tend towards heteronormative couples supporting risk factors for those individuals facing EOL without a spouse or partner (de vries, et al., 2022).

A final area of note that was found during the recruitment and post interview closing process was a consistent sharing by individual participants that they anticipated sharing their caregiving story to be beneficial and then confirmed the benefit for themselves and the hope for benefit to others. Because this was shared outside the recorded data it was not included in the findings for this study but further supports the need for postventions for caregivers that involves peer sharing including support groups or designated spaces to discuss death and EOL. This is supported by research into the benefits of spaces like Death Cafes and other online or in-person social supports for individuals who have experienced a death or want to discuss this in a space that facilitates these discussions (Gibson, et al., 2020; Miles & Corr, 2017; Miller-Lewis, et al., 2020; Moore, et al. 2019).

Limitations

While sample sizes were adequate for data saturation in an exploratory phenomenological study this sample size limits the transferability to general populations even specific to Western culture. While this data did not collect demographics of cultural, ethnic, racial, or socioeconomic backgrounds there is an acknowledgement that these would be subsets of Western culture and impactful to subscribed social norms. The intent of this study was not to create a comparative analysis of specific subsets of Western culture but acknowledges that these subset norms would be impactful on EOL care and subscribed social norms.

Recruitment utilized a support group facility for the sampling population. This would affect the outcomes of desired death communication through the grieving process reported by the participants and bias of reflection on death communication norms. This sampling population would also contribute to a bias in peer support postventions for caregivers.

Implications for Practice

Once their person died, participants found support and would then intentionally participate in death discussions reflecting on the death of their person and how that has impacted them. Further discussion and evaluation of early life interventions introducing youth and adolescents to EOL and death communication skills, emotional competence on the topic, and coping skills as well as community education and awareness of topics such as ACP and death communication skills have some validity from the data collected. Participants with longer term caregiving and further experience with death were reported as more prepared for care especially when communication in the EOL process was supported. This points to time, practice, and assistance for evaluating ACP and EOL as important to the experience not only for the caregiver but for the person dying as well.

Another implication for practice would be the consideration of peer support postventions for EOL caregivers. Grief is a part of the EOL caregiving experience after their person dies and the findings of this study supports participants sharing their stories and their death experience can be a component of processing that grief which can include assessing their own EOL. Grief peer support is impacted by avoidant social norms and would require intentional work to create and refer individuals to spaces where they could safely, openly discuss their EOL experience and grief. These could be official support groups or social and community spaces where they could share with others who are receptive to these discussions. These more informal social and community spaces would be able to serve the dual purpose of introducing people to death communication skills as well as supporting those grieving to develop educational and community supports for facilitating EOL discussions and knowledge.

Future Research

Educational and community resources on EOL would need more research to support its implementation in a death avoidant culture. Because younger individuals tend to be protected from death experiences the need for research for any school or youth interventions would be essential to support future programming and practices to facilitate it.

The postvention needs for caregivers is a subset of this population that lacks saturation of current research. All grieving people seeking care would be impacted by future research into effective interventions as they would not all be necessary exclusive to the caregiver subset. The focus of EOL care is on the individual dying but the caregiver has needs beyond this caregiving experience and will carry that experience into their life through their ongoing grief journey. Grief and caregiver postvention resources would need to have broader community support to not only create the resources where they are lacking but to also build general population knowledge of the resources when they are available to have a client base the supports ongoing funding and sustainability of the resources themselves. Research into effectiveness and necessity would be impactful to these cultural education, shifts, and resource development.

Inclusions of Western culture subsets of populations in future research of subscribed EOL discussion normal would help to understand the impact of cultural competency, cultural background, and access to resources on EOL care. This could further develop best practices for medical and community resources to support a broader demographic. All people face EOL no matter their cultural background, socioeconomic status, race, gender, or sexual orientation. All individuals deserve to have a quality of EOL and research that can acknowledge better understanding of ways we can support access to resources that support broader EOL quality. This would impact the individuals who will be facing death to the multidisciplinary team that provides care to the social norms that impact how we all understand and advocate for our EOL wishes and needs.

Appendices

Appendix A: Sample of email blast and flyer information

[Michigan support group] members,

Program staff and group facilitator, Maureen McKenzie, is conducting a Master Thesis study starting in January 2023 and is seeking participants. The study is exploring how our practices communication about death and end-of-life impacted someone's ability to advocate and care for their person who died. There are participation criteria due to the specifics of the data.

Participation criteria:

- ***Designated caregiving decision maker in the last 10 years for a friend or family member's end-of-life.***
- ***Designation of role as caregiving decision maker can be formal or informal and no requirements as to whether a decision was made on your person's behalf.***
- ***Must be a consenting adult, over the age of 18 since the time of caregiving experience.***
- ***Report as cognitively, physically, and emotionally equipped to discuss details of this experience.***

If you meet the criteria, know that participation is completely voluntary, and you can discontinue participation at any point during the study process. Participation would involve completing an open-ended interview via Zoom or at the [support group facility]. Interviews would be about an hour long and ask questions regarding **your history of discussing death with peers and family**, **your experience as a caregiving decision maker**, and **currently reflections**.

If you or someone you know are interested in participating and meet the criteria listed above, you can let your group facilitator or program staff know for Maureen to contact you or contact Maureen directly at [facility professional email address] or [facility phone number with researcher extension].

Thank you for your time and consideration.

Be well,

[Support group facility] Program Staff

Appendix B: Consent Form

Talking About Death: Exploration of the Impact of Death Communications Norms on End-of-life Caregivers

Participant Information and Consent Form

RESEARCHERS

Maureen McKenzie	Paola Leon, PhD, MSW
Principal Investigator and Graduate Student	Faculty Committee Chairperson
School of Social Work	School of Social Worker
Grand Valley State University	Grand Valley State University

You are being asked to participate in a research study. This study is part of a master thesis in social work. All information and data collected will only be viewed by the student and faculty listed here and will only be used for educational purposes. The purpose of this project is to learn about qualitative research methods, data collection, and data analysis. The box below highlights key information about this research for you to consider when deciding whether or not to participate. Carefully consider this information and the more detailed information provided below the box. Please ask questions about any of the information you do not understand before you decide whether to participate.

Key Information for You to Consider

- **Voluntary Consent**. You are being asked to volunteer for a research study. It is up to you whether you choose to participate or not. There will be no penalty or loss of benefits to which you are otherwise entitled if you choose not to participate or discontinue participation. You may discontinue participation and consent at any time during the research process.

- **Purpose**. The purpose of this study is to explore how the subscribed communications norms discussing death impact an end-of-life caregiver’s ability to fulfill their role to advocate for their person’s end-of-life wishes

- **Duration**. It is expected that your participation will last 60 minutes.

- **Procedures and Activities**. You will be asked to participate in a face-to-face Zoom interview or recorded in person at [the Michigan support group facility] on your communication norms in your upbringing discussing death and end-of-life, your experience as an end-of-life caregiving decision maker, and currently reflections.

- **Risks**. Some of the foreseeable risks or discomforts of your participation include the potential to feel uncomfortable or emotionally distressed answering some of the interview questions. Resources within and recommended by [the support group facility] will be provided for any distress or needs due to participation.

- **Benefits**. There is no direct benefit of participating in this study, but it is possible that interview questions may prompt self-reflection and care-seeking behaviors. The researchers hope to gain a better understanding of how social norms in death communication throughout life affect our ability to act and participate in the end-of-life process later in life to help discover potential assistance to people, whether through education services or health interventions.
- **Alternatives**. Participation is voluntary and the only alternative is to not participate.

1. **PURPOSE:** You are being invited to participate in a research study to learn more about the impact of how the subscribed communications norms discussing death impact an end-of-life caregiver's ability to fulfill their role to advocate for their person's end-of-life wishes. Our overall goal is to better understand how social norms in death communication throughout life affect our ability to act and participate in the end-of-life process later in life to help discover potential assistance to people. Researchers are required to provide a consent form to inform you about the study, to express that participation in this study is voluntary, to explain risks and benefits of participation, and to empower you to make an informed decision about participating. You are free to ask the researchers any questions you may have about the study and participation.

2. **REASON FOR INVITATION:** You are being asked to participate in this study because you are an adult over the age of 18 who self-reports an experience acting as a decision making caregiver to a person who died and are willing to discuss details of the experience and your communication history abut death.

3. **RISKS:** Some of the foreseeable risks or discomforts of your participation include that you might feel uncomfortable and emotionally distressed while answering some of the study questions. You will receive a handout with referrals for counseling services with this consent.

   It's possible that someone other than the researchers or faculty advisor could find out you were in the study or see your private study information. The research team takes multiple steps to ensure your confidentiality throughout the research process. We take confidentiality very seriously and will strive to make your participation in this study as confidential as possible.

   Your participation is voluntary, and you may stop participating in the study at any time without penalty to you. You may also choose to not answer any questions during the interview that you wish to not answer.

4. **PRIVACY AND CONFIDENTIALITY:** The researchers will make all efforts to keep your information confidential to the maximum extent of the law. Only the researchers conducting the study and faculty advisor will have access to your study information. There are certain instances, such as a court order, where we may have to disclose data. Your information will be kept confidential by assigning you a participant ID code to de-identify your personal identity. Your name will not be used in any study reports, and we will de-identify any information in your interview responses that can be linked to you, so that no individual participant can be identified in reports, publications, or presentations.

   All data, including audio-recordings, will be stored in password protected computer files on a secure drive.

5. **AFTER THE STUDY IS OVER:** The research team will not keep your research data to use for future research. Your name and other information that can directly identify you will be kept secure and stored separately from the research data collected as part of the project. The research team may share your research data through presentations or publication without asking for your consent again, but it will not contain information that could directly identify you.

6. **REMOVAL FROM STUDY:** Participation in this research project is completely voluntary. You have the right to say no at any time during the research process. You may also change your mind about participation at any point and withdraw from the study. There are no possible consequences for withdrawing from the study. You may choose not to answer specific questions or to stop participating at any time without penalty or loss of benefits to which you are otherwise entitled.

7. **AGREEMENT TO PARTICIPATE:** By consenting to this consent form below you are agreeing to the following:

    - The details of this research study have been explained to me, including what I am being asked to do and the anticipated risks and benefits;
    - I have had an opportunity to have my questions answered;
    - I am voluntarily agreeing to participate in the research as described on this form;
    - I may ask more questions or quit participating at any time without penalty.

8. **CONTACT INFORMATION:** If you have any questions about the study you may contact

    NAME: Maureen McKenzie PHONE: [researcher phone number]
    E-MAIL: [researcher facility email]

    If you have any questions about your rights as a research participant, please contact the **faculty chairperson, Dr. Paola Leon, by email at leonm@gvsu.edu or by phone at 616-331-6561.**

    This study has been approved by the faculty committee.

9. **PARTICIPANT CONSENT QUESTIONS:** Prior to the start of the interview, the researcher will ask you the following questions to obtain consent to participate in the research study. If you answer yes to both questions, the research will then begin recording the interview and ask the same two questions again to have your consent to participate on the audio-recording.

- **Do you consent to the audio and video recording of this interview to be used as data for this study?**

Appendix C: Interview Guide

TALKING ABOUT DEATH: EXPLORATION OF THE IMPACT OF DEATH COMMUNICATION NORMS ON END-OF-LIFE CAREGIVERS

Interview Guide

I. Introduction:

Thank you for taking the time to participate in and complete this interview. The overall goal is to gain understanding of how the subscribed communications norms discussing death impact an end-of-life caregiver's ability to fulfill their role to advocate for their person's end-of-life wishes. Today we are interested in talking with you more in depth about three areas. First, we are interested in learning more about the details of your communication norms within your family and peers, as well as specific life experiences that impacted these norms. Second, we are interested in what your experience was like as an end-of-life caregiver, including your relationship to the deceased and information about how, when, and why you were designated as the caregiver. This will include reflections back on the experiences including discussions and decisions made during this time. Last, we are interested in your reflections on the experience and what you would have done different and how your current norms of communication about death have been impacted since then.

To help answer some of the questions, it would be helpful if you could provide a pseudonym to refer to your person [*DECEASED*] and then we can start with a few general questions about you:

- *What is your age:*
- *What is your gender identity and preferred pronouns:*
- *In the simplest terms, what was your relationship to the [DECEASED]:*
- *How long ago did [DECEASED] die:*

II. Communication Norms about Death:

To start us in the conversation, I am interested in *your communications norms when discussing death in your upbringing and adult life*. First, I'd like to ask a few general questions that review your communication about death in your life:

Can you share your experience with discussing death in your childhood?
Follow-up questions:

- How did different adults talk to you about death?

- What words did they use to describe or refer to someone who died or was dying?
- Did your peers discuss death with you?

How did your communication about death change as you got older?

Follow-up questions:

- What events impacted how death was discussed as you got older?
- How did the language change as you grew older?
- What people were you comfortable talking to about death?

Probes:

- Consistencies, avoidance, curiosity

In your adult life, how was death discussed and what norms from your upbringing carried through?

Follow-up questions:

- Can you share some examples of experiences discussing death in your life?
- What were pivotal conversations about death for you?
- What conversations about death were most impactful for you?

Can you describe your experience discussing death within your family?

Follow-Up Questions:

- Was there language in these conversations that was specific to your family?
- How did this language change over time?
- What beliefs or customs in your family may have influenced these discussions?
- During your upbringing and into adulthood was there anything that changed how your family discussed death and end-of-life?

How were your experiences discussing death different with your peers?

Follow-Up Questions:

- What environments or groups created the most difficulty for you discussing death?
- What environments did it feel easiest to discuss death and end-of-life?
- What role did you tend to play in these conversations? For example, speaker, listener, observer, instigator, avoider, etc.

What experiences in your life impacted the frequency you discussed death?

Follow-Up Questions:

- Can you describe how these changes impacted the group they were within versus elsewhere in your life?
- How did you personally respond to these changes versus others?
- In what ways did this change your communication about death after that?
- What parts of your life did this impact the most?

Probes:

- Personal, professional, family, peer, etc.

III. Caregiver Experience:

Thank you for sharing your personal norms in discussing death. I'm now interested in hearing from you about *your experience as an EOL caregiver.* In your response to volunteer for this study, you identified acting as a caregiver or what some may identify as a health care proxy or advocate whether through legal designation of power of attorney, identified in a living will, or informally agreed upon. This role could consist of direct decision making, discussions with the health care team and [DECEASED], making sure the [DECEASED]'s wishes were followed, and may have been designated well before the end-of-life process formally or not.

How would you describe your relationship to [DECEASED]?

Follow-Up Questions:

- How close were to you to [DECEASED] previous to their EOL?
- How long had you known [DECEASED]?
- How had your relationship changed over time?

How did you and [DECEASED] decide to have you act as their EOL caregiver?

Follow-Up Questions:

- When and how long did it take to make the decision?
- Can you describe anything you did in response to being designated as caregiver?
- How were you designated?
- What decisions or advanced directives were you aware of in taking this role?

Probes:

- Formal: Power of attorney, living will, appointed representative
- Informal: assumed role, personal discussion

Can you describe what your primary discussions were with [DECEASED] during their EOL?

Probes:

- Such as subject, topics, specifically remembered exchanges, they do not have to specifically relate to death.

Follow-Up Questions:

- Can you describe subjects you worked to avoid?
- Can you describe subjects [DECEASED] would avoid?

How did you and [DECEASED] discuss their EOL?

Follow-Up Questions:

- What language did you use?
- How often did you discuss their death?
- What topics were you most easily able to discuss about their death?

Probes:

- Treatment plans, advanced directives, quality of death
- Meaning making, saying goodbye, spiritual, or emotional guidance
- After death preparations: financial, spiritual, physical, familial

During your EOL caregiving experience can you describe points of communication that helped you feel quipped to complete your role as caregiver?

Probes:

- With [DECEASED], health care team, family, friends, etc.

Follow-Up Questions:

- Can you describe your experience communicating [DECEASED] wishes for EOL with the health care team?
- Can you share an experience where you had to make a decision for [DECEASED] and how equipped you felt to make that decision?

IV. Current Reflections and Communication Norms:

We have talked about your past EOL caregiver experience and your communication norms about death in your upbringing and adult life. I would like us to move to your current state on both these subjects.

Reflecting back on your EOL caregiving experience, how well do you feel you understood and facilitated [DECEASED]'s EOL wishes and directives?

- What would have helped you more in your role?
- What would you change within your role as caregiver?

How has your communication about death and EOL changed since your caregiving experience?

- What has contributed to any changes in your communication about death?

That was all the questions I have for you today, is there anything that I did not touch on today that you feel would be important for me to know?

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