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What Should Be Said or Silenced: Opinions of Necessary and Inappropriate End-of-life Communication Between the Living and the Dying

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by

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ABSTRACT

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End-of-life (EOL) communication experiences between the Dying and the Living in various roles (e.g., family, clergy, healthcare providers, and hospice workers) have often been studied; however, no research has examined what people believe are necessary as well as inappropriate EOL conversation topics with the Dying. Extant studies in family communication have identified common EOL topics in retrospective accounts of previous conversations with the Dying, but no research has asked individuals with and without such experiences what they think should and should not be talked about during EOL interactions. The current study addressed this gap. Participants (*N* = 145) ages 18 through 88 years-old completed a qualitative online questionnaire comprised primarily of open-ended questions. Reported necessary topics (*N* = 558) included “reflections on life and living”; “preparation of the Dying’s transition and impending death”, and “planning for the future”. Participants reported that certain topics should be talked about (*N* = 564) because, for example, they “bring comfort to the Dying”, “honor and respect the wants and needs of the Dying”, and create a sense of closure. Reported topics that the Living

should not discuss with the Dying include those that are “negative, painful, and upsetting matters”, “address money, possessions, and inheritances”, and are about “the Living’s needs, problems, wishes, and beliefs.” The primary reasons for avoiding such topics included that by not talking about them the Living can “bring comfort to the Dying”, “avoid futile or insignificant conversations”, and those topics recognized as “selfish, and mean-spirited, in poor taste, insensitive, rude, hurtful, or greedy.” These findings increase awareness of what people believe to be necessary conversation content and existing barriers that may prevent competent interpersonal communication.

Keywords: communication, end-of-life communication, dying, end-of-life

To my husband, Andrew
and my granddaughters, Janae and Jaida

In memory of my mother, Theresa (Terry),
who inspired my interest in end-of-life communication

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Chapter 1: Introduction

One of the few certainties in life is that one day ours will end. In general, American culture views and presents death as a dark and taboo topic, one that is morbid, unpleasant, frightening, that ignites feelings of uncertainty, lack of control, awkwardness, discomfort, and denial (Keeley & Yingling, 2007). Although dying is a natural part of life, it is regarded as a melancholic and unnatural process and experience (Keeley & Yingling, 2007). The dying process and experience was once set in the familiarity of the home (Corr & Corr, 2013), but today the aging, the ill, and the dying move to assisted living residential units, nursing homes, hospitals, and community hospice centers to complete their final time, as death transitions into a medical event, rather than a family experience (Corr & Corr, 2013). At the end of the 20th century, however, research in mortality and academic programs in death and dying increased and hospice care spread, giving rise to an added awareness of care for the dying (Lee, 2008). While death has started to lose its taboo label, it still is considered one of the most difficult topics to discuss, and people often worry they will say “the wrong thing”, making the situation “worse” by upsetting the ill person (Callanan & Kelley, 1992). However, as attitudes toward death and dying continue to change, so should our approach to how we interact and communicate with the Dying in an effort to promote *good death* experiences. A good death is defined by the Institute of Medicine as “one that is free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards” (Field & Cassell, 1997, p. 1). A good death is a desired state of the Dying’s transition that requires further examination. This current

study looks to expand the research and insight surrounding the attitudes and awareness of obtaining a good death through communication.

Theoretical implications of this study include an improved understanding of what topics people believe are necessary to include in their EOL conversations with a family member or friend who is dying and why these subjects are deemed essential. A better comprehension of what topics are thought to be inappropriate to discuss with the Dying, and the underlying reasons, will also give insight to what people fear and desire when they use an empathetic lens to view what is considered holistically beneficial and harmful to the Dying. The current study also has implications for our understanding of past EOL conversations with friends or family. While extensive research in EOL communication based on experience and recollection exists, there is a gap in literature where the opinions of what are essential as well as inappropriate topics to talk about with the Dying and the reasons for them are identified, regardless of personal experiences.

Practical implications of this current study include the opportunity to enhance and improve hospice educational and care programs through a better understanding of the opinions and thoughts about communicating with the Dying. Through the knowledge gained from the current study, members of hospice teams including physicians, nurses, social workers, chaplains, and volunteers will have a heightened awareness of existing fears, anxieties, and awkwardness that the Living and Dying may have regarding EOL conversations. Additionally, counselors, therapists, and hospice and clergy members will have understanding of possible communication apprehension sources and additional insight when evaluating possible explanations for the Dying's inability to

obtain closure or peacefully transition.

In this study, I identified what are considered necessary topics in end-of-life communication between the Living and the Dying and identify what the Living perceive as necessary and inappropriate topics to include in end-of-life conversations and why they perceive them as such. While existing end-of-life communication research is extensive in communication involving healthcare providers and hospice team members and communication including the family of the Dying, there is no existing literature that examines the opinions of what people believe communication between the Dying and family members and friends should look like (and what it should not look like). Therefore, the review of literature for this study covers EOL communication literature that focuses on retrospective accounts of the conversations the family members and friends had with their dying loved one.

Chapter 2: Literature Review

End-of-Life (EOL) communication in families has been a focus of research for almost 40 years (Keeley, 2004a); however, extant studies that examine EOL communication between the Dying and their family and friends center on actual experiences and memorable messages of final conversations that occurred between the Dying and their surviving loved ones (Generous & Keeley, 2014; Keeley, 2004a, 2004b, 2007, 2016; Keeley & Baldwin, 2012; Keeley & Generous, 2015; Keeley, Generous, & Baldwin, 2014; Keeley & Yingling, 2007) rather than the *opinions* about the content of communication between the Living and the Dying, what is considered necessary or inappropriate, and the reasons behind these beliefs.

EOL communication, comprised of verbal or nonverbal messages, is considered quite significant to the Living and Dying, and while talking with the Dying may be emotionally challenging, the interactions are found to be an important part of the dying process that may offer comfort to the dying individual (Keeley, 2004a) and help the surviving loved one through the grief period while finding acceptance of the death (Keeley et al., 2014). Research in EOL communication has identified perceived benefits for having EOL conversations, including reinforcing relationships between the Living and the Dying during the terminal time (Keeley, 2004a) and creating lasting memories for surviving children and adolescents that help them cope with their loss long after the passing of their loved one (Keeley et al., 2014). During the terminal time, the Living are provided opportunities to resolve conflicts and mend painful past experiences, strengthen relationships through dialogue, obtain needed closure with the Dying, confirm and affirm their identity, and clarify their life path (Keeley & Yingling, 2007, p. 6). While participating in EOL conversations with the Dying can be beneficial for both the Living and the Dying, it is sometimes challenging for the Living to remain engaged and mindfully present in these conversations because of our cultural tendency to be uncomfortable with silence, a preoccupation with our own feeling or thoughts, and anticipatory grief (Foster & Keeley, 2015). However, it is not likely that communication alone is significant to both parties, but the content of the communication that is most meaningful. What we discuss with the Dying can influence the communicative interaction and direction of our relationship and the journey through the Dying's last days. Detecting when the Dying person is ready to talk and understanding *what*

subjects he or she is willing or ready to talk about is key, according to Callanan and Kelley (1992).

Topics of Discussion in End-of-Life Conversations – What is Said

Recent research has identified common messages found in EOL conversations between family members. Through a qualitative interview study, Keeley (2004a) reported five types of messages included in EOL conversations between adult family members: (a) love, (b) identity, (c) religious and spiritual, (d) routine/everyday talk, and (d) difficult relationship issues. Messages of love are needed by the Living and the Dying, and according to Keeley and Yingling (2007), it is important that these messages are explicit, whether delivered verbally or nonverbally. Everyday messages can strengthen a relationship's bond and acknowledge that the Dying are still important and still alive. Everyday talk was also identified as the most common type of conversation that took place during EOL communication. Everyday talk reintroduced a sense of normalcy, and the participants reported the value and significance of talking about "everything" and engaging in discussions with the Dying about daily life, such as school and daily activities, with the intention of using dialogue to create new and lasting memories (Keeley et al., 2014).

Messages of identity that were received by children from the Dying focused on providing advice and expectations for the future care of others, an acknowledgment of the child/adolescent's worth, and self-confirmation, and conversations that incorporated a sharing of history from the dying family member generated a sense of connection between them and the child /adolescent (Keeley et al., 2014). Children/adolescents advised the Living to stay positive, seek outside support, and to confirm and maintain

their relationship with the Dying through spending time together and participating in everyday communication with each other (Keeley & Generous, 2014). Another common topic to surface in the end-of-life conversations between children/adolescents and dying family members was messages of love communicated verbally and nonverbally, which are most often communicated with direct language such as “I love you” or “I will miss you” (Keeley et al., 2014).

In another study, Keeley (2004b) examined EOL messages that focused on religious faith and spirituality. Survivors’ recollected shared messages with their dying loved ones that reflected two primary themes in this study: validation-comfort and validation-community. Most religious faith and spiritual messages came in the form of validation and reflected comfort or community, with the emergence of three rules of conduct for living and coping: “(a) cope with life’s challenges after a loved one is gone, (b) be involved in the death and dying process, and (c) enact or live your religion or spirituality” (Keeley, 2004b, p. 97). Keeley (2004b) reported that when religious beliefs or spirituality became a part of EOL conversations, the messages functioned “as validation to comfort those left behind and validation to acknowledge death’s role as part of the human community” (p. 99).

Keeley et al. (2014) have also looked specifically at EOL conversations between dying adults and surviving children and adolescents (ages 12-18). They reported four of the five same themes found in the adult study, excluding relationship issues. As in the adult study, among the messages of greatest salience was the exchange of words that delivered feelings of love. Based on their final conversation experiences with a dying family member, children/adolescents advised others in their age group of what they

believe to be important and necessary communication messages to be shared between the surviving child and dying family member.

According to Keeley and Generous (2014), confirming the relationship with the dying family member is also salient to children/adolescents. Participants in their study advised other children/adolescents to “spend as much time as possible with the dying person, participate in everyday communication, give verbal and nonverbal expressions of love, be physically present, and show altruism” (p. 310). These messages are considered to be *necessary*, as children/adolescents noted feelings of *regret* when they felt they did *not* engage in the mentioned communication with the Dying or wished they had done so more.

Research has also shown that there are three primary categories found in the messages that relay that the Living are offering support, comfort, and assisting the Dying (Manusov & Keeley, 2015). Through Manusov and Keeley’s (2015) retrospective interviews it was found that the Living also believed “nonverbal cues were important for emotional expression as relational messages (of both love and connection), and interaction management (which included interaction responses and greetings/goodbyes)” (p. 396). Additionally, a category of “social support (including assistance, comfort, and companionship” (p. 404), which was used as a transition function, was revealed. However, messages that demonstrate social support are sometimes communicated nonverbally between the Living and the Dying. Nonverbal communication may become more of a necessity as death becomes more imminent. As the Dying’s illness progresses, it often hinders their ability to communicate verbally (Foster & Keeley, 2015). Nonverbal cues typically exchanged during final conversations

include messages of love and affection, expressing experienced emotions including "joy, fear, sadness" allowing the individuals to express the fear that comes during the terminal time and at the end-of-life (Manusov & Keeley, 2015, p. 393). According to this study *connection* was "reported to be a very salient aspect of end-of-life interactions with family members and described as consistent with the relational messages people send to one another—often nonverbally—that signal their bond to one another" (p. 396). In relational messages such as connection, nonverbal communication included kinesic cues (e.g., dancing together as done in the past), while facial behavior and gaze conveyed messages, as well. Messages between the Living and the Dying may be exchanged nonverbally and verbally, but there continues to be an awkwardness and discomfort when it comes to communicating about death and dying.

In response to a nationwide need for further focus and an intervention to promote conversations about end-of-life wishes between friends and family, several online and community resources were created (Lambert South & Elton, 2017). Out of this movement, the website *Death over Dinner* (DoD) evolved and is used as a resource to encourage death and dying conversations in small family and friend groups (Hebb, 2013). A recent focus group study that examined how family and friends communicate with each other about death and dying in a dining gathering based on using the framework of DoD, found that while there were more similarities than differences in how participants communicated with family and friends, participants tended to be more candid in their conversations with friends versus family members (Lambert South & Elton, 2017). The study recognized that the Dying desire a "good death" and use tactics

for coping, and report that some topics confuse or elicit fear (Lambert South & Elton, 2017).

Death and dying is an anxiety-producing taboo topic in many cultures that might prompt fear and discomfort when mentioned in conversation (Abdel-Khalek, 2002). Conversations surrounding the topic can lead to distress and awkwardness that might provoke individuals to respond with various coping mechanisms. Humor might be used to alleviate the uneasiness, while spiritual reassurance might reduce the tension, and a separation from thinking about death might be necessary to provide a sense of contentment and ease for those engaged in communication (Lambert South & Elton, 2017).

While topics should never be forced in end-of-life conversations, the Living should demonstrate an interest in communicating with the Dying by showing a willingness to talk by beginning a conversation with a statement such as, “I’m sorry to hear that you’re so ill,” waiting for a response, and then *listening* (Callanan & Kelley, 1992, p. 59). Callanan and Kelley (1992) stress that, “it’s never wrong to speak of your love and concern” (p. 59), and we should not put too much emphasis on worrying about saying the “wrong” thing. There are some topics that are not only important but necessary to talk about with the Dying; discussions that the Living consider essential to have with the Dying. While studies have examined the conversation topics that appear most frequently in EOL communication, these reviews are based on retrospective narratives from individuals who have all experienced EOL conversations with a Dying family member or friend. The current study seeks the opinions of adults who might or

might not have participated in an EOL conversation and asks the following research question:

RQ1: What do individuals think are necessary topics for friends and/or family to talk about during EOL conversations with the Dying?

Avoided Topics in End-of-Life Conversations – What is Kept Silent

There are times when the Living might experience an awkwardness and uncertainty in determining if or how to talk about some topics and statements made by the Dying. As the Dying move closer to death, it is common that they see, hear, and talk about things that are unfamiliar or unrevealed to the Living. The Dying might focus their attention and speak to someone who the Living cannot see – perhaps someone who is no longer living. This experience may lead the Dying to include the Living in a conversation about what they are experiencing. While the Dying are typically not frightened or uncomfortable with these experiences, the Living may not know how to respond (Callanan & Kelley, 1992). According to Callanan and Kelley (1992), the Living should not argue with the Dying's proclamations nor should they debate the Dying's reality.

Sometimes the topic of death itself is completely avoided in conversation when denial is observed in terminal patients (Planalp & Trost, 2008). Family members, friends, and healthcare providers are continuously challenged with the uncertainty of what ought to be said to the Dying. According to Addington and Wegescheide-Harris (1995), the ambiguous environment combined with the personal difficulty of dealing with death when interacting with the Dying makes communication challenging yet important. "Whatever is said and not said, and how it is said, has a profound effect on the patient"

(p. 270). Candid and forthright conversations regarding the Dying's medical condition or prognosis was once viewed as inappropriate, as the open discussion of these topics was once believed to result in the diminishment of the Dying's hope and will to live (Corr & Corr, 2013). Unfortunately, this belief still exists among the Living and the Dying (Callanan & Kelley, 1992).

While the Dying might oppose discussions involving their impending death, often family members and significant others prevent or complicate end-of-life conversations as a result of their denial of or inability to accept the bleak prognosis or end-of-life care preferences of the Dying (Larson & Tobin, 2000). When a loved one suffers from a terminal illness, family and friends may choose to avoid discussing topics that are informational in nature such as "(a) diagnosis and the illness trajectory, (b) decision-making, and (c) death and dying" (Caughlin, Mikucki-Enyart, Middleton, Stone, & Brown, 2011, p. 417). Individuals tend to believe that talking about death to an ill person will upset the patient and elicit negative feelings, such as sorrow, while, not saying anything could be interpreted as a lack of caring (Callanan & Kelley, 1992). Some believe that discussing the patient's illness or impending death with them will upset their dying loved one or add stress that will deteriorate their health beyond its current condition. Conversely, some avoid talking about what might seem to be trivial issues (e.g., workplace issues) with the Dying for fear of offending them during a serious time. Yet others fear if they say nothing, the silence itself will cause an awkwardness (Morrow, 2018).

Caughlin et al. (2011) found that adult children who lost a parent, in this case to lung cancer, avoided discussing topics that were informational in nature, such as

diagnosis, illness trajectory, and prognosis, with the dying parent as a means of "(a) protecting self and others, (b) maintaining hope and optimism, and (c) maintaining idiosyncratic family standards" (pp. 417-418). Medical decision-making related to the dying patient and direct conversations about death and dying, also considered informational in nature, were evaded to protect the Living from negative emotions. Avoiding certain topics might serve to protect them from the harsh and painful reality of their loved one's impending death. The Living might fear discussing information regarding their loved one's prognosis will infringe on their desire to maintain hope or following what their family considers proper or good communication. Dialogue that addresses the impending death of one of the individuals was often found unbearable and made the imminent death *real*. Avoiding this topic was believed to preserve optimism and emotionally protect the Living and the Dying.

In addition to informational topics, emotional topics are also avoided by the Living, as demonstrated in a study that examined family communication and coping in response to a parent's terminal diagnosis and eventual death (Caughlin et al., 2011). Such topics included expressions of love for the parent, the anticipated emotional impact of loss after the parent's imminent death, and inquiries regarding the dying parent's feelings about their prognosis and treatment trajectory. Generous and Keeley (2016) also examined intentionally avoided topics in EOL conversations that included negative relationship characteristics, the impending death of their loved one, and personal information that might be considered unacceptable by one party, such as sexuality or past histories. The extant research that reviews topics of avoidance is limited because it only explores the actual experiences of those who have participated

in EOL conversations. This examination looks only at the topics that individuals intentionally avoided, without expanding the results by including the opinions of what is believed to be inappropriate topics to discuss, regardless of EOL communication experience.

Furthermore, provided reasons are limited. Existing studies indicate various reasons for topic avoidance in EOL conversations. One potential reason identified in the research is that avoided topics, if discussed, might elicit fear or uncertainty (Lambert South & Elton, 2017). For example, Lambert South and Elton's (2017) participants reported that conversations about organ and whole-body donations caused them discomfort, and dialogue regarding palliative and hospice care produced a lack of trust and fear of receiving insufficient care, a loss of curative treatment, and a loss of hope of survival, since hospice care is often perceived as surrendering to death. Terminal patients may believe if they discuss palliative or hospice care, they are affirming an imminent death. The discussion of end-of-life and after death planning provoked uncertainties, as participants believed in the value and importance of advance directives and wills, but they remained doubtful that family members would successfully carry out their stated wishes. According to Generous and Keeley (2016), participants intentionally avoided certain topics during EOL conversations to protect themselves, their loved ones, and their relationships. Relational characteristics, such as belief and value differences between the Dying and the Living impacted the Living's choice of what to evade during discussions with the Dying. Additionally, the physical, psychological, and emotional condition and strength of the Dying influenced the Living's decision to avoid specific topics of conversation with their dying loved one.

As indicated, the conversation topics and reasons for avoidance are limited because they are based on actual experiences, rather than the opinions and extensive possibilities that have not yet been reported or examined in a study. As a result, there remains room to obtain additional answers defining what topics are avoided in EOL conversations and the reasons behind the desire to evade them; therefore, I asked a second research question:

RQ2: What do individuals believe are inappropriate topics for family and/or friends to talk about during EOL conversations?

Chapter Three: Method

To address my research questions, I used a qualitative approach that generated rich descriptive data to assess the end-of-life conversation topics that participants deemed necessary and inappropriate with the Dying. I included open-ended questions in an online survey that encouraged detailed responses from the participants. According to Merriam (2009), qualitative research approaches seek to understand how people construct meaning and make sense of their world and experiences. Through this qualitative approach I collected participants' opinions of what topics should/should not be talked about with the Dying as well as their explanations as to *why* they had such opinions. This in-depth inquiry gathered unique and thorough responses that would not have been possible through a quantitative approach. Participants elaborated and provided responses that included rich content that I analyzed to obtain an explanation and understanding of the responses. Participant narratives demonstrated general and specific attitudes toward conversation topics that they believed should and should not be a part of dialogue with the Dying.

Participants

Participants (*N* = 145) in this study primarily identified as women (76.6%, *n* = 111), but men completed the survey, too (22.8%, *n* = 33; one person did not report their gender identity). They ranged in ages from 18 to 88 years (*M* = 39.77, *SD* = 17.13). Participants included 52 undergraduate students in an introductory interpersonal communication course who on average had completed about 3 years of college. Almost 8% of the students reported being enrolled part-time (*n* = 4), and the remaining 92% were full-time (*n* = 48). Additionally, 81.4% of the total participants reported their race as White/Caucasian (*n* = 118), 4.8% as Asian (*n* = 7), 4.1% as African American (*n* = 6), 3.4% as Hispanic (*n* = 5), 2.8% as Middle Eastern (*n* = 4), 1.4% as Mixed (*n* = 2), and 2.1% unreported (*n* = 3).

Recruitment

The recruitment methods used to solicit participants included posting a call that included a link to the questionnaire on social medial sites such as Facebook, Twitter, and LinkedIn, and the Communication, Research, and Theory Network (CRTNET) (see Appendix A). Additionally, a community hospice care center shared the posting of the call with hospice care team members and others as they saw appropriate. The survey was made available to UWM students currently enrolled in the Communication 101 course, and eligible students had the opportunity to earn extra credit comparable to 1 unit of research credit through the completion of the survey. Communication professors and instructors were asked to post the letter of recruitment on Desire to Learn (D2L) or via email message to students. Recruitment from these various means provided a diverse group of participants with varied backgrounds, ethnicities, culture, values, gender, age, and religious and spiritual beliefs.

Procedures

After seeing the call for participation in the college course or the social media posts, interested individuals clicked on the link provided, which took them to the informed consent page (See Appendix B). Once they read, understood, and agreed to the conditions (i.e., that they were 18 years or older), they were taken to the https://www.surveymonkey.com/mp/survey-vs-questionnaire (See Appendix C), which was approved by the university's institutional review board (IRB) and was conducted through the Qualtrics survey software. The questionnaire was expected to take approximately 30 minutes to complete, based on estimation. If participants reported that they wished to earn extra credit in their communication course, they were taken to a separate questionnaire that collected their name, email, instructor name, and section number.

Questionnaire

The questionnaire consisted of demographic and open-ended questions. Demographic questions asked for participant age, gender identity, ethnicity, student status, year in school, part or full-time school status, employment status, and if they worked part or full time. Participants also reported if they had ever had conversations with the Dying. If they responded yes, I asked them to tell me what their relationship with the most significant person who had passed away was, as well as their closeness level with them, using the Inclusion of Other in the Self Scale (Aron, Aron, & Smollen, 1992).

Participants also responded to a series of open-ended questions. First, I asked participants to provide up to five topics they believed are necessary to discuss during

EOL conversations, as well as up to five topics they believed should *not* be discussed with the Dying. For each topic they reported, I also asked them to share and explain why it should or should not be discussed (i.e., their reasons); therefore, each participant could report up to 10 topics and 10 reasons.

Data Analysis

I downloaded the data collected from the questionnaires, cleaned it (e.g., deleted incomplete surveys), and conducted my analyses. I started the process by archiving half the data for future coding application, a qualitative research procedure called referential adequacy (Lincoln & Guba, 1985) where codes are developed on a portion of the data and then applied to the remainder. If the codes "hold up" with their application, then the scheme is considered valid. If any alterations are needed after application, ideally they are minor (e.g., slight changes in the labels and/or descriptions of codes). In my case, I was able to apply my codes to the second half of the data without any significant revisions; therefore, my scheme can be considered trustworthy.

After archiving the data, I initiated an inductive, open coding process to derive codes for necessary and inappropriate topics as well as participants' reasons for each. I started by reading the first topic, deciding its substance, assigning it a code, and then moving to the next topic datum, deciding its substance, and comparing it to the first to decide if they were similar or different. If they were similar, I moved on to the next datum, but if they were different I decided on a new code. This process is called the constant comparison method (Glaser & Strauss, 1967). When labeling codes, I used descriptive (i.e., using researcher terms to describe the data) and invivo (i.e., using participant language choices to create codes) coding to identify common and repetitive

patterns in the respondents' answers (Saldaña, 2016). I used this process across the first half of the data, and after I was satisfied that I had exhausted my list of codes, I applied them to the second half of the data as described above. After I coded the entire dataset, I then went about collapsing codes to come up with a more manageable list of codes. In the first phase of coding, I created 22 codes to identify the various categories for what *should* be talked about with the Dying. I then looked for themes across codes so that I could cluster them together into useful categories of codes and divided them into three themed umbrellas.

I must note one unforeseen challenge in analyzing these data. I designed the survey's format so that the participants listed each topic and reason in separate boxes (i.e., the first topic that they considered necessary was entered in the first box and then they provided their reasoning for why the topic was necessary in the next one; the process was repeated up to topic and reason #5). While I instructed them to separate and individually list topics and reasons in appropriate boxes so that each box is associated with only one response, some participants entered their topic and reason collectively in one box. In these cases, if the following response boxes were empty and several responses were listed in the preceding box, I coded the responses as separate topics (e.g., four responses listed in one box was assigned four separate boxes) and coded accordingly. If a box included more than one response and the other response boxes also contained responses, I recognized and counted the first entry listed in the one response box.

In addition to using referential adequacy, I establish data trustworthiness through demonstrating credibility and dependability (Shenton, 2004). Credibility was created

through triangulation through the use of a wide range of participants. Additionally, an attempt to ensure honesty in the respondents was made, as the participation in this study or an obligation to complete the survey was not mandatory; therefore, participants elected to participate in the study out of free will. Distinct method instructions, definitions, and clearly-stated measures increases the dependability of this study and allows it to be repeated (Shenton, 2004).

Risks and Benefits to Participants

Risks to participants were considered minimal, although there was a possibility that participants felt emotional discomfort if their responses were based on the recollection of their experiences, and questions that may have triggered recollections of loss was painful for them, especially if their loss was recent. After completing this survey, it was possible that they felt distressed. To help alleviate stress the participants might have experienced, I shared the contact information for the Milwaukee County Mental Health Service and the Norris Health Center, located on UWM campus. This information was located in the informed consent form/page of the survey.

There were no benefits for participants except the opportunity to advance research in this area and possibly learn more about themselves and their attitudes and anxieties about EOL communication and final conversations. Also, currently enrolled university students who completed the survey could earn one unit of research credit point in their Communication 101 course.

Chapter 4: Results

The findings of this survey are organized in a framework that first describes the extent of the participants' experience with death and EOL conversations with significant people in their lives, as well as the intimacy level and relationship connection with the

significant individual whom they reference in the survey as someone who they engaged in an EOL conversation. A report of the topics identified by participants as ones that are necessary to include in EOL conversations with a dying friend or family member and why they believe this will follow, along with the topics that participants believe are inappropriate topics that should not be discussed with the Dying and the reason for the participants holding these beliefs will. This chapter will conclude with a report of any exceptions participants believed would affect or change what they believed be reported.

These participants reported knowing an average of 4.14 people who have died in their lives (*SD* = 3.82) ranging from 0 to 32 people. Of the total number of participants who completed the survey (*N* = 145), 71.7% (*N* = 104) reported having had a conversation with someone significant to them who was dying. While 31% of the participants who engaged in end-of-life communication did not indicate their specific relationship to the dying individual, 19.3% reported the significant person to be a family member (*N* = 28), 11.7% reported their mother (*N* = 17), 9.7% indicated their father and 9.7%, a grandmother (*N* = 14 each), 6.2% specified a friend (*N* = 9), 4.8%, a grandfather (*N* =7), and the remaining 7% indicated another type of family member.

Opinions Regarding Necessary Topics in EOL Conversations

To answer RQ1*: What do individuals think are necessary topics for friends and/or family to talk about during EOL conversations with the Dying?* I derived codes from the participants' reports and identified three necessary topic themes: *reflections on life and living, preparation for death,* and *planning for the future*. I discuss each topic cluster in detail below as well as provide examples from participants' responses along

with the topic number and reason number from their surveys (e.g., Participant 1, T1, R1).

Reflections on Life and Living. These topics have an overall positive tone of life celebration, relationships, and reminiscing – a review of life's value. Of the total number of necessary topics reported (*N* = 568), I classified 41.37% (*n* = 235) as reflections on life and living. A large number (*n* = 72) of these included topics specifically pertaining to memories, reminiscing, and reflecting on the past, childhood stories, history, and family narratives. These topics review life with a focus on the significance, success, accomplishments, and experiences of the Dying. Advice and life lessons from the Dying are sought and shared. A 28-year-old man who experienced an EOL conversation with his grandmother reported, "I think it's important to talk about their last words and the stories that they want to share before dying" [Participant 63]. A 51-year-old man who had experienced an EOL conversation with a family member reported that necessary topics include recalling "the good times. Remembering life events, childhoods, family, listening to their story" [Participant 53], while a 41-year-old woman who had an EOL conversation with her father reported that it is necessary to talk about "things about their life and experiences that could help shape the living's view or actions" [Participant 50].

Another subset of reflections on life and living include topics surrounding expressions of love, care, appreciation, gratitude, thankfulness, value, and fond feelings between the Dying and loved ones (*n* = 65). One example came from a 21-year-old male college student who has not had a conversation with someone who was dying, but reported, "I think it is necessary to tell [the Dying] how they have impacted your life and

tell them genuinely what you think of them because they deserve to know how they have been an influence in your life" [Participant 136, T1, R1]. A 20-year-old man who also had not had a conversation with someone who was dying reported that it is important to, "let [the Dying] know how much you appreciate and love them" because, "it's important for that person to go in peace knowing they're loved" [Participant 108, T1, R1]. A 25-year-old woman who had EOL conversations with a family member of her significant other reported that these conversations should include sharing "who you are to one another (i.e. what you mean to them, what they mean to you)." She explained:

> Talking about their life experiences provides them with a moment to reflect. This moment of reflection is not just meaningful for them, but also meaningful to the person talking to them. It gives the dying person an opportunity to share important pieces of wisdom, lessons learned, words of advice, and also have the satisfaction or reliving and retelling the story in a meaningful way. [Participant 20, T1, R1]

Reflections on life and living also included the Dying's final wishes, wants, thoughts, expectations, and how their remaining time should be prioritized (*n* = 51). Several participants felt it was important to talk to the Dying about how they wished to spend the remainder of their time. A 34-year-old woman who had experienced an EOL conversation with a family member reported, "Their final wishes, although I feel that this discussion should be ongoing and begin long before a person is actively dying. I feel that it is important to follow a loved one's final wishes as closely as possible" [Participant 70, T1, R1]. A 58-year-old woman who had also experienced an EOL conversation with a family member reported, "Talk about goals and what type of quality

of life [the] person has at that time. Talk about HOPE, a different hope than trying to stay alive forever!" [Participant 89, T1, R1].

Some necessary topics related to life reflections also included the discussion of the Dying's children and family memories and relationships (*n* = 18). Conversations concerning the Dying's children and future custody and placement of the children, if necessary, was considered an important topic to discuss with the Dying. Participants also felt that in many cases, talking to the Dying about their family would bring happiness to the Dying. Everyday talk in which interests, hobbies, and humor were shared (*n* = 12) between the Living and the Dying was thought to be an imperative part of EOL communication. Everyday talk provides a sense of normalcy, distraction from the gloom of imminent death, and affirms the Dying are still active contributors among the living. A 21-year-old man who never experienced an EOL conversation reported:

> I think it's important to just have normal conversations with them about normal things in the world - sports, music, whatever you want. It's important because people probably don't want to think about how they're dying, so this can help distract from that and keep them feeling like everything's pretty normal. Most people might get pretty sentimental, and they'll probably want a break from that. [Participant 139, T2, R2]

EOL conversation topics identified as necessary also included the most meaningful moments and degree of Dying's life satisfaction (*n* = 9). A 19-year-old woman who had never engaged in an EOL conversation believes it is important to ask the Dying "if they are content with where their life has taken them" because "they should be happy with their life's journey" [Participant 101, T5, R5]. In addition to these topics, a

few participants thought the revelation of secrets or unknown information and final words and messages from the Dying is significant to both the Dying and the Living (*n* = 8). They believe that the Dying's sharing of kept secrets is beneficial to the Dying for release and closure and also to the Living who gain new information that could impact their lives. A 21-year-old woman who had a final conversation with her grandmother learned valuable information during their talk and reported, "My grandma hid money in a tube sock (almost $10,000) and I would have hated to have somebody thrown that sock away and she would've hated it too" [Participant 24, R3].

Preparation for Death. A second cluster of necessary topics fell under what I labeled "preparation for death" (*N* = 198) and reference the Dying's transition and impending death. Topics of faith and spirituality (*n* = 46) make up the majority of this cluster. An example of this came from a 25-year-old woman who had an EOL conversation but did not specify with whom. She reported:

> I would talk about how they are feeling in there [sic] given situation. I would ask if they are scared or unsure of if there is an afterlife. Then I would MAYBE talk about my faith/God experiences depending on how those first few questions went. If I sense they don't want to talk about anything, I will just try to converse about something more joyful. [Participant 78, T1]

She explained her response:

> I have a religious view- thus I believe in an afterlife. I'm not dead and I cannot officially really say there is an afterlife but I will say I have had personal experiences with God when I was in fearful times. Having

> conversations that comfort the person who is dying is morally right regardless if it's about the afterlife or not. If my religious experiences help someone feel safe and not fearful of death then I will have the conversation. [Participant 78, R1]

Another example of faith and spirituality was given by a 32-year-old woman who had an EOL conversation with her grandmother. She reported that it is necessary to talk to the Dying about "what they believe exists afterlife". She explained:

> I think talking about the unknown journey into afterlife regardless of the persons [sic] views, religion, etc. is an important process in accepting death (given there's time for a discussion like that). It emotionally prepares the person for the next step into death, and brings comfort, peace, eases fear of death. The conversation could be even as simple as "we will see each other again one day, friend", which supports that there is more beyond death for that person. [Participant 140, T2, R2]

A second set of topics under "preparation for death" addressed the process of assisting the Dying with dying and essential end-of-life care (*n* = 38) such as ensuring comfort and pain management, saying good-bye, letting go, releasing their loved one, and expressions of closure. A 56-year-old female who engaged in an EOL conversation with her mother stated that a necessary message to communicate to the Dying is "letting them know that it's okay to die. Because I think sometimes people who are dying try to hang on for their loved ones" [Participant 130, T1, R1]. A 31-year-old woman who never had an EOL conversation also found it necessary to communicate a release to a Dying loved

one. She noted it was important to tell the Dying, “that you will be alright while they are gone. Tell them it's alright to pass. Sometimes patients get worried how their loved ones will cope without them” [Participant 81, T1, R1]. Similar sentiments were shared by another participant. A 53-year-old woman who had an EOL conversation with her parent also expressed the significance in talking to dying loved ones and “allowing them to let go and be comfortable leaving you”. She also stated, “I believe that in my cases of sitting with my parents as they passed that they were relieved to know we would be ok after they passed and that it was ok to leave and end their suffering” [Participant 27, T1, T2]. Responses indicated that participants believed it is necessary to provide consolation and fulfill the emotional needs of the Dying as they prepare for their transition.

Participants also reported that it was necessary to let the Dying speak about whatever they desired, share their feelings and express desires that might help bring closure. An example of this comes from a 41-year-old woman who had an EOL conversation with her father and felt one of the most significant questions to ask the Dying is, “Are you ready?” [Participant 13, T3]. Responses revealed that the Living often think people should ask the Dying questions to survey their wants and needs, allowing the Dying to lead and set the rules of what topics are acceptable or permissible.

Responses in this cluster also indicated the Dying should be asked whom they want to see, whom should be privy to their condition, and how they want people to interact with them and support them. A 35-year-old woman reported

that the Dying should be asked who they want present in their life to help them prepare for their death.

> In my experience, some individuals have wanted to be surrounded by family and friends until the very end. They wanted to laugh, joke, and see faces. In other experiences individuals have slowly said their good-byes and preferred to have only their spouse with them during their last days. Others have removed everyone from their life as they wanted to be remembered as a healthy person and did not want family and friends to see them get sicker and sicker. [Participant 123, T4, R4]

Lastly, participants shared the Dying can also be helped along with the death process by simply listening and being present without necessarily bringing up any topics at all. A 56-year-old woman who had engaged in past EOL conversations with family members reported:

> People die as they live. You can't fix life in the last days or weeks of someone's life but you can be open to conversations, keep an open heart and be supportive. Listening and advocating are important parts of these conversations. Let the dying person lead the conversations but it may be appropriate to provide opening prompts about things which will affect comfort and welling. [Participant 110, AE]

Planning for the Future. The third and last category of the total EOL topics deemed necessary is *planning for the future* (*N* = 135; 24.19%). The responses in this category differ from the preparations for death category in that the latter refers to inner preparation (e.g., emotional, spiritual), whereas this

category emphasizes post-death arrangements and future plans required as a result of the death. A portion of the reported topics in this cluster centered on financial, will and estate planning, child custody and placement, distribution of possessions, and getting affairs in order. A 45-year-old woman who had an EOL conversation with her mother who reported it is necessary to talk to the Dying about “their wishes for after death.” She explained:

> You need to know what this person wants you to do after they pass. Funeral, memorial or nothing. Burial, cremation, donate body to science (I know people who have chose[n] this option). These things are important to the dying person. I think knowing their wishes will be carried out the way they want is comforting to them. [Participant 3, T1, R1]

Inquiring if the Dying’s affairs are in order might seem like a difficult and awkward topic to discuss, but many participants agreed that it is important and necessary. A 30-year-old woman who had never had an EOL conversation, stated, “A person's affairs (disputes unsettled, open accounts, etc.) lead to the most animosity after death, so while many people don't wish to discuss it in the end, it is the most crucial for the people left behind” [Participant 12, T1, R1]. Part of having one’s affairs in order might include having appropriate legal documents prepared to carry out their wishes. A 35-year-old woman reported that the most necessary question to ask someone who’s dying is, “Do you have a will and/or other legal documents in place?” She explained:

> All of the individuals I have known who have passed (whether from a long-term illness or unexpectedly) have not had legal documents in place.

> After their death it caused SIGNIFICANT hardship (emotional and financial) to settle their respective estates. Having this in place would have been a huge gift to the grieving. [Participant 123, T1, R1]

A 21-year-old man provided another example of a necessary discussion topic involved in planning for the future when an individual is dying that also covers fulfilling the Dying's wishes and legacy. He reported:

> It's good to discuss what they want you to do once they're gone. Things like a will or inheritance, and what to do with their possessions. You want to make sure that you and other family members or friends respect their wishes and carry on their legacy how they want it. [Participant 139, T1, R1]

Reasons: Why Certain Topics Are Believed to be Necessary

The participants responded with reasons for the opinions they shared regarding the topics they believed should be included in EOL conversations with the Dying. Of the total provided reasons (*N* = 564) 54.3% (*n* = 306) indicated that talking about necessary topics should bring comfort to the Dying, 21.3% (*n* = 120) reflected that topics should honor and respect the wants and needs of the Dying, 9.8% (*n* = 55) argued that topics should bring a sense of closure, 7.8% (*n* = 44) represented other miscellaneous reasons, and 7% (*n* = 39) said topics should be chosen as a way to avoid future conflict and stress for the Dying's family. The most prominent group of reasons focused on providing comfort for the Dying. One example of this was given by a 30-year-old woman who reported:

> It's important to make sure the person who is dying is comfortable both physically and emotionally. Some people may want time alone even though their family members want to be there with them. I think if you're a caretaker you try to do anything possible to ensure the person who is dying is comfortable. [Participant 21, T1, R1]

Another example is given by a 25-year-old woman who stated:

> Spending silent moments together allows both parties to experience a moment of just BEING with the dying person. It allows them to FEEL one another's presences, which is a memory and moment that the living person can reflect upon and always keep with them. For the dying individual, I imagine such an interaction might bring them a sense of peace or calm, just knowing that the living person is there in the moment with them. [Participant 20, R5]

A second set of reasons captures the need for topics to maintain respect and honor for the Dying and their needs, wants, dreams, wishes, and legacy. A 28-year-old male who had an EOL conversation with his grandmother reported:

> People put off the topic of dying wishes for fear that it will be uncomfortable or somehow offensive, but this is an important topic to clarify what the person wants to happen with their belongings or something else that is important to them. Yes, there are legal services and processes for some of this, but many people never go through this formal process, or perhaps they have additional wishes they want to share in their moments of dying. [Participant 63, R2]

A 43-year-old man who experienced an EOL conversation with his grandmother summed up this reason description when he stated, “this is their journey not mine and they need to discuss how they want their journey to end” [Participant 34, R1].

Other reasons included avoidance of possible future family conflict and stress and the need to provide closure for the Dying through resolving issues and unfinished business. A 41-year-old woman reported a reason to have a conversation with the Dying about forgiveness is “to be able to in essence ‘wipe the slate clean’ for both the person dying and the living” and create a sense of closure. [Participant 50, R1] Another woman participant reported:

> This acts as a situation where the dying individual can unpack “would haves” or “could haves” and come to terms with these moments. It also serves as an achy reminder for the living person to learn from these experiences or painful regrets and learn from them. [Participant 20, R4]

Participant responses covered a plethora of topics they believed were necessary to discuss with a dying family member or friend, and they provided a variety of reasons for holding these opinions. An assortment of opinions and reasons as to what should not be discussed with the Dying was also shared by participants. Miscellaneous topics that showed up in responses from participants, indicating beliefs on what should be discussed with the Dying included an inquiry as to the Dying’s understanding of his/her condition and assumptions that the Dying is completely aware of their prognosis. A 55-year-old woman who experienced an EOL conversation with a friend reported:

> I think it is important to ask the dying person what their understanding is of their disease process. We shouldn't make the assumption that "you are dying" is apparent to the person. It may be apparent to the doctor and to some family and friends that the disease has progressed and cannot be cured or put in remission or even slowed down. A hospice understanding is that "I am dying." So I think it is important to ask the person, "what is your understanding of where you are at with your disease?" And then listen. And use their answer to gauge the next topic. If they say, "I think I can still beat this." Then it is clear that we aren't going to talk about hospice. If they say, "There aren't any more treatments. I am dying." Then is it is clear that we can then talk about the next level of care- hospice (comfort, dignity, new hope). [Participant 129, T1, R1]

Other participants thought certain topics should be addressed to avoid future conflict or stress in the family after the loved one has died. Knowing the Dying's wishes can spare family members the discussion and debate of making EOL decisions for their loved one. A 58-year-old woman who had an EOL conversation with her grandmother noted, "Hopefully they have advanced directives and other financial items taken care of but if they don't it pays to ask. To help them wrap up their life and honor their wishes" [Participant 88, T4, R4].

Opinions Regarding Inappropriate Topics in EOL Conversations

In regard to RQ2: *What do individuals believe are inappropriate topics for family and/or friends to talk about during EOL conversations?* participant responses included the following topics (*N* = 429): Negative, painful, upsetting information (*n* = 256;

59.67%); Money, finances, possessions, inheritance, and death (*n* = 64; 14.91%); The Living's own needs, problems, wishes, and beliefs (*n* = 47; 10.95%), and Other (*n* = 34; 7.92%). A relatively small number of participants argued that no topic in EOL conversations should be considered off-limits (*n* = 28; 6.53%).

The most frequently noted inappropriate topic in my data are those that would cause distress for the Dying. Topics described as unpleasant and hurtful to the Dying included regrets, fears, shortcomings, faults, mistakes, blame, criticism, and judgments. Negative matters also included talking about the Dying's pain, illness, bleak prognosis, physical appearance, impending death, final arrangements, and all they will miss once they are gone. Over half of the participants believed it was important to spare the Dying from experiencing further anguish by avoiding conversations that would generate emotional distress. A 40-year-old woman who had an EOL conversation with her mother reported that she believed the Living should avoid talking with the Dying about "the things they didn't accomplish (never finished college, didn't save enough money, etc.)." She explained, "accomplishments are not the most important pieces of life. People can experience regret, feelings of failure, guilt, etc.---about things that they now can do little about" [Participant 73, A1, A1R]. A 50-year-old man who experienced an EOL conversation with a friend whom he considered very close reported that family and friends should not engage in conversation with the Dying about "anything hurtful, malicious, or revealing that disturbs their peace and comfort." He also stated as a reason:

> The primary focus should be on the person who is experiencing end of life. While we are all effected, they should be in control of the process and

> experience it on their own terms. It is a matter of dignity. Those that are effected [sic] that are not at the end of life, should not be selfish and make the experience about themselves or their agenda. [Participant 57, A1, A1R]

Talking about money, finances, wills, and possessions was considered greedy and insensitive, while sometimes relating a message that the Dying was not important or of focus and interest, but rather what s/he would leave behind. A 46-year-old woman who had an EOL conversation with her grandfather, stated that “money” is a topic never to be discussed with the Dying and that discussing “who will get their stuff is insensitive” [Participant 32, A1, A1R], and a 58-year-old female agreed that it is not a good idea to discuss material possessions with the Dying. She reported:

> Never speak about "Who is going to get his/her big red truck, money, etc..... Humans are connected to many of their material things and believe this is what makes them a successful person. The problem with talking about material is "we can’t take it with us" and its [sic] really not important in the end. [Participant 189, A1, A1R]

Participants also reported that the Living talking about their own concerns is inappropriate for EOL conversations with the Dying. Participants related that it was insensitive for the Living to center these discussions on their own issues, problems, wishes, and grief. This included imposing or forcing one’s own views, beliefs, and opinions such as end-of-life wishes, religion, spirituality, or an afterlife on the Dying. An example of this is given by a 32-year-old woman who

had an EOL conversation with her friend whom she considered very close. The participant reported that it was inappropriate to talk to the Dying about “your own wishes for how they die.” She explained:

> It is not your place to tell someone how to die. You might have the belief that life support shouldn't be administered to someone with a terminal condition, but if they want life support, they should have it (and vice versa). [Participant 40, A1, A1R]

A 31-year-old woman who also experienced an EOL conversation with a friend reported that it was inappropriate to talk about “one’s own problems” with someone who is dying. She stated:

> The transition from life to death is all-consuming and the person should be able to focus completely on themselves at this time. This does not include telling the person what they have done for you, what they mean to you, or even news you want to share with them before they are gone. But bringing your personal issues into their mind or telling them you cannot cope with them is not supportive of their journey. This might require getting this help elsewhere so you are able to remain open and honest with your loved one. [Participant 67, A1, A1R]

Participants reported a variety of “other” topics considered unsuitable for EOL communication. Inappropriate topics in this category included discussions of politics, sex, and platitudes or statements such as, “I know how you feel,” or “Don’t worry.” Yet, despite the lengthy list of opinions that define unfitting EOL conversation subjects, some shared the opinion that *all* topics are appropriate to

discuss during these final dialogues. A 47-year-old woman who had an EOL conversation with her mother reported on this, “I don't think any topic should be off limits at all. Some might avoid topics that have to do with problems that the survivor is or will have, but even those shouldn't be purposely hidden” [Participant 43, A1]. A 30-year-old woman who also had an EOL conversation with her mother had a similar opinion:

> There really aren't many things that absolutely shouldn't be talked about with someone who is dying. If you're with them through death, you're probably close with them and as a result, most topics are fair game (though sex, exes, and other potentially contentious topics are good things to avoid). [Participant 60, A2, A2R]

Reasons: Why Certain Topics Are Believed to be Inappropriate

The participants responded with reasons for why certain topics should be considered inappropriate to talk about with the Dying. Of the total provided reasons (*N* = 364), 47.53% (*n* = 173) should be avoided to help bring comfort to the Dying; 14.83% (*n* = 54) recognized that some topics are futile at a time when death was impending (i.e., they are insignificant, unimportant, without point, and too late to change anything or make a difference); 6.25% (*n* = 40) indicated that some topics are inappropriate because they are selfish, mean-spirited, in poor taste, insensitive, rude, hurtful, or greedy; 7.42% (*n* = 27) indicated that avoiding certain topics in conversation demonstrated a way of displaying respect for the Dying; 5.22% (*n* = 19) of the responses suggested that some topics are inappropriate because they avoid thinking and talking about the impending death;

and 3.85% (*n* = 14) believed all attention should be on the Dying rather than any other matters and certain topics direct focus away from the Dying. Slightly under 10% of the reasons (*n* = 37) fell into a miscellaneous category (e.g., the belief that no topics are off limits).

Some Topics Provide Comfort and Peace. The most prominent group of reasons assert that the Dying should have peace and positivity, and certain topics are inappropriate because they cause stress, worry, fear, anxiety, burden, and negativity. A 30-year-old female who had an EOL conversation with a family member reported the reason she believed it was important to not discuss anything that the Dying does not wish to discuss during EOL talks. She stated:

> I really believe that someone's dying moments should be spent how that person wants to spend them. If a family member wants to use this time to get something off of her/his chest and the dying person isn't interested in that conversation, then it's not the time. [Participant 21, A1R]

The reasons provided by participants clearly noted that creating a sense of peace for the Dying was a priority for the Living. A 34-year-old woman who participated in EOL conversations with her father explained why she believed the Dying should not be told the "ways they let you down or disappointed you in life" because "the past can't be changed". She also reported, "I don't want to cause them to be filled with regret or remorse in their last days/moments" [Participant 26, A1, A1R]. A 43-year-old woman also believed the Dying should be in a peaceful state and thought finances was an inappropriate topic to discuss with a dying loved one "because that's a stress they don't need. It's not going to help

them find peace at the end" [Participant 34, A1, A1R]. A 69-year-old woman reported that bringing up issues pertaining to family discord or unresolved conflict "may create an uneasy or anxious moment when the atmosphere should be one of comfort and security" [Participant 144, A1, A1R]. A 56-year-old woman who had an EOL conversation with her mother summed up the sentiments of most of the participants when she reported, "passing away should be a personal time hopefully special time for family not one that's ruined by something that caused more pain then [sic] necessary" [Participant 6, A4R].

Some reasons provided by the participants indicated that the desired peaceful state that was sought was not only for the benefit of the Dying. Friends and family members were also seeking a peaceful and positive experience during the final visits with their dying loved ones. A 26-year-old woman believed it was best to avoid discussing "anything that could be interpreted as unpleasant avoiding" during EOL conversations "because you want your last memory with them to be as happy as possible" [Participant 31, A1, A1R]. Whether the positive, stress free, peaceful interaction was for the benefit of the Dying, the Living, or both, it was by far the highest-ranking reason for avoiding what participants identified as inappropriate EOL conversation topics.

Some Topics are Insignificant and Futile. Other reasons for considering certain topics inappropriate in EOL conversations were based on the low rating of their importance and significance. Participants felt that issues that were either no longer significant, could not be changed, or futile, were not worth talking about with their dying loved one. Conversations surrounding negative memories and

events from “the past” were viewed as undesirable topics best left in the past. Disputes, disagreements, and differences were among subject matter considered inappropriate for EOL conversations. A 66-year-old woman reported, “There are always things in life that we can agreed [sic] to disagree on; however, there are some discussion that will never be resolved” [Participant, 95, A1R]. Participants who reported similar reasons stated that there was no point in bringing up superficial topics (e.g., politics) that were irrelevant to someone who is dying.

Some Topics are In Poor Taste. Participants also reported that some topics are inappropriate because they are in poor taste or are selfish, greedy, mean-spirited, rude, insensitive or hurtful. At times, the desire to talk to the Dying about money or possessions was interpreted as a sign of selfishness or greed. A 43-year-old woman reported, “I find it selfish and insensitive to ask the dying to parcel out their belongings” [Participant 68, A1R]. A 32-year-old woman also reported, that “talking about benefits of any financial gains upon the dying person's death would seem to the dying like you didn't care about them as a person but are looking forward to perks of their potential death” [Participant 140, A2R]. Other topics besides inheritance were found to be insensitive to the Dying, as demonstrated in a report from the same woman:

> Bragging about things that are going on in the living person’s life that really don't correlate to the dying person's direct influence in their life would be insensitive and rude. It would completely disregard the dying's feelings and how their death is impacting people after they pass on. [A3R]

Some Topics Should be Avoided to Show Respect for the Dying. While the above reasons explained how certain topics are considered disrespectful to the Dying, other reasons explain that some discussions are used to demonstrate respect for the Dying through focusing all attention toward the loved one and allowing them to direct the conversations. A 26-year-old woman who had not experienced an EOL conversation reported:

> If someone's dying, you should just respect their wishes. If they don't want to talk about what they want for theri [sic] services after death anymore, then don't make them. If they say they don't want to discuss treatment options anymore, stop trying to make them. [Participant 38, A3R]

The same participant also added, “just respect their preferences and wants and needs as much as possible and try to not let your wants and needs overpower theirs.”

A 59-year-old woman felt there are exceptions to every scenario, and there might come a point during the Dying’s terminal time when saying nothing is acceptable, and perhaps desired. Allowing the Dying to direct the communication path might be the best route. She reported:

> A few years ago I lost my husband after a ten-month battle with pancreatic cancer. We talked a lot about all aspects of death and dying: about his wishes, about our marriage, about everything. Until at one point, about five days before he died, we agreed that we had said everything we had needed to say. He told me at that point, "Let's just let our hearts do the talking." I think this was in part, because we knew the end was near, and it

was becoming more difficult for him to communicate. But it was also the case that we had already discussed so many things. I think he was concerned that it was becoming more difficult on ME to talk about him dying. One of the most poignant things he ever said to me was, "I know you're going to miss me, but you need to know, I don't want to leave you either." It was beautiful, precious, and oh so sad. But, I realize, not everyone is as verbal as we were and for some words don't come as easily. So my bottom line is - follow the dying person's lead. Talk about what THEY want to talk about and leave other things alone. [Participant 65, Exceptions]

Insensitivity. A 25-year-old woman who had an EOL conversation with the family member of her significant other believes these conversations should avoid topics that would cause the Dying to feel sad. She reported, “If there is a topic that emotionally upsets the dying individual, this is unfair to bring up to them. At the end of one's life, it is selfish and hurtful to discuss topics that bring sadness to that person” [Participant 20, A2, AR2].

Respect through Avoidance. Some topics are deliberately avoided to acknowledge the wishes and demonstrate respect for the Dying. A 32-year-old woman who had an EOL conversation with a friend, described why she believes it is important to avoid topics and choices that have already been decided on and determined by the Dying. She reported:

My mom has told me she doesn't want life support and wants to "just go," and that makes me feel physically ill... but it's not my call. It's her call. I

wouldn't want her to choose how her life ends out of guilt or obligation. It should be solely her decision. [Participant 40, A1R]

Facing the impending death of a loved is trying for both the Living and the Dying, and often it is a topic that many choose to avoid. A 41-year-old woman found her most difficult conversation was in one of the EOL conversations she had with her dying father. She reported:

> The hardest conversation I ever had was with my Dad when his body was starting to fail him. His oxygen tank was set at the maximum setting and he just couldn't catch his breath. Everyone else around me refused to tell him that it was his body, not the machine. That conversation is one I will never forget. Looking into his eyes as I said it isn't the machine, Dad, it's you - was very difficult but also helped all of us acknowledge that death was coming whether we wanted to admit or not. [Participant 50, AE]

Miscellaneous Reasons. Sometimes intentions are good, but outcomes do not match. Included in the category of miscellaneous reasons for avoiding topics are various explanations that participants provided for the avoidance of specific topics in EOL conversations. While each not prevalent enough to establish their own code, they are worth mentioning and providing an exemplar. One participant stated that continuing to advise a Dying person to eat or drink when their body no longer desires it, should be avoided. A 31-year-old woman stated, “This may force the patient to try to eat and become sick or aspirate” [Participant 81, A4R]. As with other topics in EOL communication, what may

seem to the Living like helpful advice, might be emotionally or physically harmful to the Dying, despite the intent.

Chapter 5: Discussion

The provided responses in this current study are the opinions of those who are sharing their perspective of what they believe is necessary, desired or wanted and inappropriate, undesired or damaging for the Dying. They reported what they believe the Dying would want and not want to talk about, and why they think such things.

Participants believed that the most significant reason to include necessary topics and avoid inappropriate ones was for the primary reason of protecting the Dying from any form of negativity that would threaten their experience of a “good” and peaceful death. The comfort and peace of the Dying was identified as a main priority for the Living when selecting topics of EOL conversations, consistent with previous literature (Keeley, 2004).

What Should Be Said

In the current study, participants reported necessary topics that were classified in three categories: (1) reflections on life and living (2) preparing for death and (3) planning for the future. Topics under reflections on life and living included reminiscing, recalling childhood stories, and chatting about hobbies and interests – attempts to surround the Dying with joyful memories and reminders of the good in their lives. The Living pulled from the experiences and memories of life, to bring comfort and happiness to the Dying. Death, which is unknown and at times frightening to us, is replaced with a review of the familiar – life. Reminders and declarations of positive and fond feelings and emotions are shared with the Dying. Expressions of love, caring, appreciation, gratitude,

thankfulness, and value are communicated with the intention of bringing comfort and affection. Declarations of love, through affirmation, reconciliation, and altruistic gestures have been found to be the most significant during EOL conversations (Keeley, 2004a). Like past literature, the current study reveals the importance of expressions of love from the Living to the Dying as a part of necessary EOL communication. Affirmation was demonstrated through the sharing of fond feelings for the Dying, expressions of gratitude and thankfulness, and an appreciation for the Dying's role and impact in the life of the Living. Attempts to obtain reconciliation and offer forgiveness for past wrong-doings and differences serve as messages of love, as they indicate an effort to improve the relationship between the Living and the Dying and confirm the Living's value of the Dying and their relationship. Altruistic gestures and behavior, as indicated in existing literature (Keeley, 2004a) validate the Living's love for the Dying through actions and efforts in which the Living place the Dying's wants and needs before their own. These gestures were often demonstrated through focusing on the comfort and care of the Dying and allowing the Dying to lead conversations and choose topics that brought them pleasure.

A life review and recollections of the past remind the Dying that their life had value and made a difference. Memories, reminiscing, and reflection on their history, childhood, success, and accomplishments offer the reassurance of the Dying's significance and relevance in the world. Their influence and impact are celebrated through the Living's search and acceptance of their advice and life lessons. The Dying's shared life stories, talk of their children and family relationships demonstrate the gesture of leaving their thumbprint on the earth.

Consistent with past studies, everyday talk and routine messages that take place between the Dying and the Living was prevalent and considered significant in EOL communication. While the current study did not examine the value and impact of every day talk involving children/adolescents, adult participants indicated the significance of this communication in their discussions with the Dying. Every day talk acknowledges that the Dying are still among the Living while giving both parties a break and escape from talk that surrounds illness and an impending death. These conversations help maintain relationships and a sense of normalcy. They sustain familiar communication for the Living and the Dying (Keeley, 2007).

Conversations focused on preparations for death included discussions of end-of-life care and decisions about comfort and pain management and curative versus palliative treatment. Spiritual conversations that focused on the Dying's faith, included topics surrounding hope, religion, death, and requests for clergy. Beliefs about creation, evolution, God, reincarnation, and an afterlife comprised what was considered necessary spiritual end-of-life conversations with the Dying. Consistent with past studies, spirituality was viewed by participants as an important topic of EOL conversations, and according to existing literature, is noted as the third most common topic the Living have with the Dying (Keeley, 2007); however, while participants of the current study found spirituality to be an essential part of their dialogue with the Dying, some believed it is only appropriate if the subject and personal religious beliefs are not invasive and forced on the Dying.

While preparing for death was seen as an essential part of communication for the Dying, planning for the future and beyond death was seen as a necessary step that

would also assist or help the Dying, ultimately relieving them of stress. Discussions pertaining to arrangements for the body, post-death wishes, including burial, cremation, and funeral services, as well as organ donation decisions were considered important topics in EOL conversations. Having the Dying's affairs in order (i.e., finances, personal belongings, child custody/placement, wills, trusts, life insurance, estate planning, and locating vital records) as well as determining how the Dying wish to be remembered and how the Living will grieve and continue living were considered critical conversation topics that would not only alleviate stress and possible conflict for the Living, but would impact their bereavement and demonstrate respect for the Dying by honoring their wishes. A past study indicated that when survivors participated in retrospective interviews, they wished they had discussed post death arrangements with the Dying (Generous & Keeley, 2016).

What Should be Avoided

Reflecting similar findings of past studies, the current study revealed that the Living strive to alleviate painful and uncomfortable situations for the Dying. The efforts to avoid negative topics that would cause the Dying to experience melancholy feelings, fear, anxiety, shame, or guilt were considered inappropriate by the Living. Again, topics that would in any way cause emotional, psychological, and possibly physical distress were defined as topics that should not be discussed with the Dying. Discussions surrounding finances, possessions, inheritance, and debt were considered inappropriate, insensitive, greedy, and mean-spirited, with a focus on insignificant material items rather than the life and value of the Dying. Participants also believed that a focus on oneself, including feelings of grief, despair, one's own problems, life issues,

needs, or wishes, demonstrated selfishness, as the focus was to be directed on the Dying and their needs.

While many participants believed it was important and necessary to discuss final arrangements with the Dying, others believed the topic to be inappropriate and uncomfortable. Most participants felt that negative and unpleasant topics, news, or feelings that may be upsetting or hurtful to the Dying, such as their regrets, fears, shortcomings, faults, mistakes, blame, criticism, or judgment, were considered taboo topics to discuss with the Dying. However, some participants believed that there were no topics that should be considered “off limits” when speaking to the Dying. Other research also indicates that topics such as Dying and negative relationship characteristics were thought by some to be topics to avoid *and* topics that the Living wished they would have discussed with the Dying (Generous & Keeley, 2016). Some participants of the current study thought that the Dying should lead the direction of conversations and the Living should avoid discussing anything the Dying did not want to discuss, indicating there is a strong desire of the Living to empower the Dying and protect them from further strife. Perhaps the empathy and compassion from the Living stems from the belief that the Dying is already carrying life’s heaviest burden, and the realization that the Living will eventually become the Dying, carrying the same load

Practical Implications

Findings from this and future research can be used to augment our understanding of what are deemed necessary and unacceptable topics in EOL communication. Results can also be used to expand interpersonal communication training and educational programs for healthcare providers and hospice workers to

enhance the support and service provided to terminal patients and their family members. While physicians believe that there is no one definition of a *good death*, because what is required to obtain this experience varies and is unique for each person, the death experience is shaped by the Dying, family and friends, and healthcare providers (Steinhauser, 2000). Experiencing a good death lies in the psychological challenge of how to relate to the Dying while they are dying and through this time, how they relate to the Living (Cooper, 2016). There is diversity in how the Dying view a good death and how they respond to the normative expectations surrounding death and dying. Five categories of normative expectations of death and dying identified in a study included open communication in which dying patients with a life expectancy of three months or less indicated the significance of communication during the last months of their lives (Goldsteen, Houtepen, Proot, Abu-Saad, Spreeuwenberg, & Widdershoven, 2006). The Dying's attitudes toward discussing death varied, as did their feelings toward other discussion topics, but despite the individual thoughts about invited or rejected conversation topics, communication itself remained a normative expectation surrounding and contributing to a good death. While what defines and creates a good death is clearly individual, the consensus is that it is comprised of a peaceful state that is free of emotional, psychological, and physical pain and distress. Making strides toward enhanced competent communication between the Living and the Dying is moving in the direction of strengthening and improving relationships and creating meaningful and memorable moments for both the Living and the Dying as they move together through the life's transition. The results from the current study can be used to identify common opinions defining what people consider to be salient and necessary

topics to include in their EOL conversations with family members and friends.

Chapter 6: Limitations and Future Research

Limitations

The current study had some limitations. First, the online survey does not allow for follow-up questions about the answers, and requiring responses be provided through writing rather than verbal responses, as in an interview, might have limited the answers the participants offered. Verbal responses might have included greater detail and more sharing. Next, participants provided fewer topics that were considered inappropriate than topics that were classified as necessary. The reduced responses for inappropriate topics could be related to a limited number of specified topics that are viewed negatively in our culture (e.g., death, greed, conflict), whereas the topics that are positive are likely to cause one to feel good; however, not all positive perceptions are shared and may not bring happiness to everyone, but they also will not create sorrow. In other words, there are fewer, yet certain, topics that will carry negativity. It is also possible that by the time the participants completed the first section of the questionnaire and prepared to begin the final section, which asked for the inappropriate topics, the participants had become fatigued, at this point. The selected method might have limited the responses, whereas interviews, focus groups, or ethnographic observations might have encouraged more in-depth responses. Also, the majority of the sample consisted of Caucasians who identified as females. This sample does not provide a complete representation of the population, as men and members of other ethnicities and cultures might respond differently to this subject. Furthermore, the current study limits the participants to the Living, not including the Dying or their perspective.

Future Research

Future research is needed to continue the review and calculation of topics with correlated reasons. Participants reported topics and reasons in sequence in this study, but I did not analyze them as paired; rather, due to time restraints, I treated reasons separately from topics. Future research might look at what topics and reasons coincide together. Further examination of EOL conversation topics, inquiring if participants believed that some topics that are defined as negative topics could or should be shared with the Dying if they felt there was a way to communicate the information without a negative outcome.

While the tensions of openness-closedness, acceptance-denial and other contradictions managed in EOL communication have been examined (Afifi & Robbins, 2015; Keeley & Generous, 2015) through the lens of Relational Dialectics Theory (RDT) (Baxter & Montgomery, 1996), RDT 2.0 has not been used to examine EOL communication and the meaning making of discourse. RDT 2.0 can be used as the framework for examination while identifying and understanding the presence of competing discourses (Baxter & Norwood, 2015). It could also serve as a lens to see how individuals make sense of determining what are necessary topics to include in conversations with the Dying and what participants believe to be inappropriate or topics that should not be included in discussions. The utterance chain of interaction includes proximal already spoken and proximal not yet spoken utterances, based on past experiences, while distal not yet spoken and distal spoken utterances determine appropriateness and can be used to examine how the Living decide what should and should not be spoken to the Dying. EOL conversations can be examined with the consideration of the influence of the relational histories between the Living and the

Dying. Additionally, centripetal versus centrifugal forces and discourse can be reviewed when analyzing data results that indicate the Living's desire to sacrifice and place all focus and attention of needs to bring comfort to the Dying.

The Theory of Motivated Information Management (TMIM) (Afifi & Robbins, 2015) could also be used as the framework for future studies in EOL communication. Through this structure, the interpretation, evaluation, and decision phases can be used in determining how decisions are made regarding what should and should not be discussed during EOL conversations. Specifically, this framework might work best in exploring information seeking in end-of-life decision making (e.g., treatment trajectory and hospice enrollment) between the Dying and their loved ones or healthcare providers.

Conclusion

It is important to continue studying what individuals believe to be necessary and inappropriate topics of EOL conversations to share with the Dying so we might improve the ability to detect, determine, and better understand the emotional needs of the Living and the Dying that might enhance their experiences through life's transition. Identification and comprehension of the reasons behind the Living's desires and fears of EOL communication can help scholars, healthcare providers, and hospice team members determine the needs of the Dying and their loved ones and guide them through decision making processes that can lead to quality interactions and a good death experience that is satisfying and beneficial for the Dying and the Living.

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Appendix A

Recruitment Post

ONLINE SURVEY STUDY about Necessary and Inappropriate End-of-Life Communication Opinions

I am recruiting participants to complete a questionnaire for a study titled, “What should be said or silenced: Opinions of necessary and inappropriate end-of-life communication between the living and the dying” (UWM IRB#18.218). This research aims to understand what the Living perceive to be necessary conversations to have with the Dying during the end-of-life period, as well as what is deemed inappropriate subject matter.

If you agree to participate, you will be asked to complete a survey that will take approximately 30 minutes to complete. The questions will ask about what you feel is necessary and inappropriate to discuss with someone who is dying. If you are a UWM student, you may be eligibe to earn extra credit in a Communication course comparable to 1 unit of research credit through either by particiapting in the suryey OR writing a two-page, double-spaced essay describing the potential benefits of continued research in end-of-life communication.

There is a possibility that you may feel emotional discomfort. Questions about this topic might be painful or emotionally uncomfortable for you, especially if you experienced a recent loss of someone close to you. If you are asked a question you do not want to answer during the survey, you do not have to answer that question, and you are not obligated to complete the questionnaire.

Email me if you have questions or click on the link below if you wish to complete the survey.

Please click on the link to begin the survey.

https://milwaukee.qualtrics.com/jfe/form/SV_8xhJGtQczgbNt9r

Thank you!

Mary Chris Dantzler (dantzle2@uwm.edu)

Graduate Student, University of Wisconsin-Milwaukee

Department of Communication

Appendix B

Consent to Participate

University of Wisconsin-Milwaukee
Informed Consent to Participate in Research

Study title: What should be said or silenced: Opinions of necessary and inappropriate end-of-life communication between the living and the dying

Researcher[s]: Dr. Erin Parcell, Ph.D. and Mary Chris Dantzler – M.A. Graduate student, Department of Communication

We're inviting you to participate in a research study. Participation is completely voluntary. If you agree to participate, you can always change your mind and withdraw. There are no negative consequences, whatever you decide.

What is the purpose of this study?

We want to understand what people think are necessary, appropriate and inappropriate conversation topics to have with the dying.

What will I do?

This survey will ask questions about your opinions on what you believe to be appropriate and necessary and what you consider to be inappropriate topics to include in end-of-life conversations with someone who is dying. It includes questions about your opinions on end-of-life communication and end-of-life communication you have experienced. The survey will take about 30 minutes.

Risks

- Some questions may be very personal or upsetting. There is a possibility that you may feel emotional discomfort recalling your own personal experiences. Questions may trigger recollections of experience with death and might be

painful or distressing to you, especially if your loss was recent. You can skip any questions you don't want to answer,or stop the survey entirely.

- Online data being hacked or intercepted: This is a risk you experience any time you provide information online. We're using a secure system to collect this data, but we can't completely eliminate this risk.
- Breach of confidentiality: There is a chance your data could be seen by someone who shouldn't have access to it. We're minimizing this risk in the following ways:
    - Data is anonymous for non-students. No identifying information will be collected (e.g., names) with the data, only for extra credit, which will be collected via a separate survey.
    - We'll store all electronic data on a password-protected, encrypted computer.
    - We'll keep your identifying information separate from your research data, but we will be able to link it to you. We'll destroy this link after we finish collecting and analyzing the data.

After completing this survey, it is possible that you may feel distressed. Milwaukee County Crisis Service offers a 24/7 mental health crisis service number (414-257-7222) that can be used for emergency counseling and referral information, if needed. The contact number for the Norris Health Center, located on UWM campus is 414 229-4716.

Possible benefits: Benefits include making a contribution to advance research in this area and possibly learn more about yourself, and how you participate in final conversations during end-of-life. Results of this study may also benefit hospice care workers to support the communicative and emotional needs of the dying and their

families by providing a better understanding of how people think about end-of-life communication.

Estimated number of participants: 100

How long will it take? Approximately 30 minutes.

Costs: None.

Compensation: None, unless you are a current UWM Communication student in a class offering participation in this study for extra credit. If this is the case, you will earn 1 unit of research credit.

If I don't want to be in this study, are there other options? If you are a current UWM Communication student, instead of participating in this survey, you can earn the same amount of extra credit by writing a 2-page, double-spaced essay describing the potential benefits of continued research in end-of-life communication.

Future research: De-identified data (all identifying information removed) may be shared with other researchers. You won't be told specific details about these future research studies.

Confidentiality and Data Security

We'll collect the following identifying information for the research (students only):

- Your name
- Your email address
- The communication class and section number you're enrolled in
- Instructor name

This information is only necessary for students who wish to receive extra credit. Students will be directed to a separate survey to provide this information.

Where will data be stored? On the researchers' computers and the servers for the online survey software (Qualtrics).

How long will it be kept? Two years.

Who can see my data?

- We (the researchers) will have access to de-identified (no names) unless you are a UWM Communication student receiving extra credit for the completion of this survey (this information will be collected separately from the survey). This is so we can analyze the data and conduct the study.
- The Institutional Review Board (IRB) at UWM, the Office for Human Research Protections (OHRP), or other federal agencies may review all the study data. This is to ensure we're following laws and ethical guidelines.
- We may share our findings in publications or presentations. If we do, the results will be de-identified (no names). If we quote you, we'll use pseudonyms (fake names).

Contact information:

For questions about the research, complaints, or problems: Contact Mary Dantzler, dantzle2@uwm.edu.

For questions about your rights as a research participant, complaints, or problems: Contact the UWM IRB (Institutional Review Board; provides ethics oversight) at 414-229-3173 / irbinfo@uwm.edu.

Please print or save this screen if you want to be able to access the information later.

IRB #: 18.218

IRB Approval Date: 03/16/18

Agreement to Participate

If you meet the eligibility criteria below and would like to participate in this study, click the button below to begin the survey. Remember, your participation is completely voluntary, and you're free to withdraw at any time.

- I am at least 18 years old

Appendix C

What should be said or silenced: Opinions of necessary and inappropriate end-of-life communication between the living and the dying Questionnaire

The purpose of this survey is to identify what people believe to be necessary topics that the Dying and Living should include in their end-of-life conversations and what is believed to be inappropriate subjects to share. It is not necessary for you to have any experiences talking to the Dying to complete this survey.

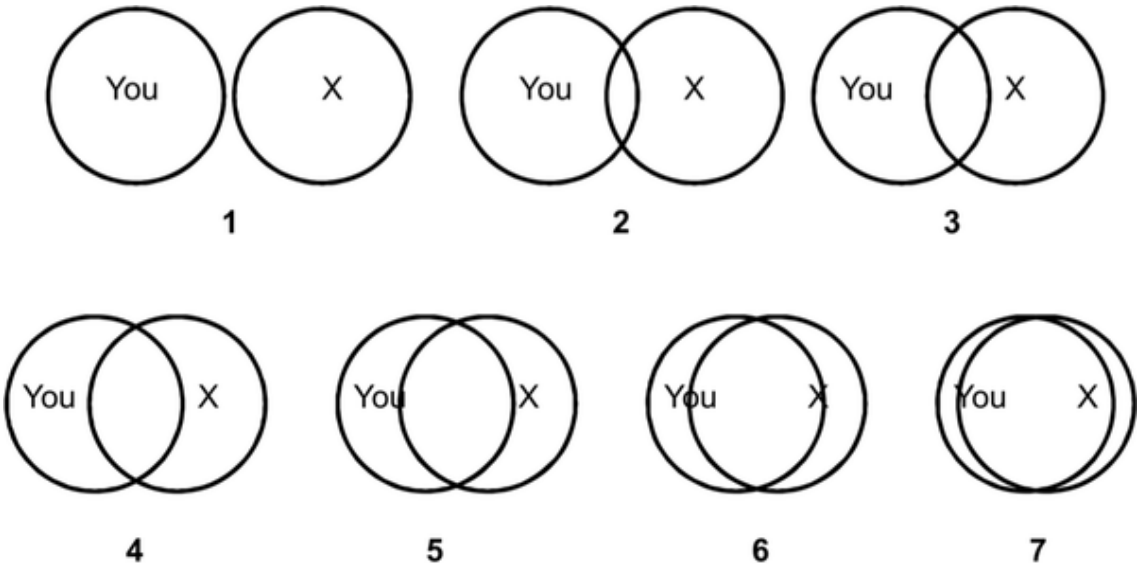
1) What is your age?____years
2) What is your gender?
    a. I identify as a woman.
    b. I identify as a man.
    c. I identify as non-binary.
    d. I identify in another way.
3) What is your ethnicity?
4) Are you currently a college student?
5) If you are a college student, what year are you?
6) Are you a part-time or full-time student?
7) What is your work status?
8) What is your relationship status?

9) Okay now we want to know about your experiences talking to people who were dying. How many people who were close to you (that is, a significant person in your life) have died?

10) Have you ever had a conversation with someone close to you that was dying?

11) Think of the person who was MOST SIGNIFICANT to you if you have had a conversation with more than one person who was dying. Who was this person to you (e.g., friend, family member, romantic partner, spouse)?

12) Which image best represents the relationship YOU had with that person (X)?



13) Now we want to ask your opinions about what topics should and shouldn't be talked about in these situations. We will ask you separately what these topics are and why you think they should and shouldn't be talked about (up to 5 topics in each category). We first want to know what topics you SHOULD be talked about with the dying. What is one topic you think is necessary to talk about with someone who is dying?

14) Why do you think this topic is necessary to talk about with someone who is dying?

15) What is another topic that you think is necessary to talk about with someone who is dying?

16) Why do you think this second topic is necessary to talk about with someone who is dying?

17) What is another topic you think is necessary to talk about with someone who is dying?

18) Why do you think this third topic is necessary to talk about with someone who is dying?

19) What is another topic you think is necessary to talk about with someone who is dying?

20) Why do you think this fourth topic is necessary to talk about with someone who is dying?

21) Why do you think this fourth topic is necessary to talk about with someone who is dying?

22) Why do you think this last topic is necessary to talk about with someone who is dying?

23) We now want to know what topics you think SHOULD NOT be talked about with the dying. What is one topic you think should NOT be talked about with someone who is dying?

24) Why do you think this first topic should NOT be talked about?

25) What is another topic you think should NOT be talked about with someone who is dying?
26) Why do you think this 2nd topic should NOT be talked about?
27) What is another topic you think should NOT be talked about with someone who is dying?
28) Why do you think this 3rd topic should not be talked about?
29) What is another topic you think should NOT be talked about with someone who is dying?
30) Why do you think this 4th topic should not be talked about?
31) What is a final topic you think should NOT be talked about with someone who is dying?
32) Why do you think this last topic should not be talked about?
33) Are there any exceptions that you believe would affect or change what you believe is considered necessary or inappropriate conversation topics with the dying? If so, please explain.
34) Is there anything else you'd like to share that would help us understand your viewpoints on how to talk to the dying?