

FINAL CONVERSATIONS FROM THE MILLENNIAL GENERATION

HONORS THESIS

Presented to the Honors College of
Texas State University
in Partial Fulfillment
of the Requirements

for Graduation in the Honors College

by

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San Marcos, Texas
December 2017

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ABSTRACT

This thesis aims to collect final conversations between millennials and their loved ones and discern the common themes that arise. Although much research has been done on final conversations (FC), millennials' communication at the end of life has yet to be explored. Millennials are a unique generation in that they have grown up with social media, and with it, access to communication with people around the world at their fingertips. They may have never had to say goodbye to someone because they will always have the ability to begin a conversation on online social media, through text, or through phone call. With that being said, when they have never had to have a FC with childhood friend that moved, a millennial saying goodbye to a dying loved one may be one of the first instances of a goodbye with a permanent communicative end.

This study used a qualitative approach to research and utilized a standard, open-ended interview process to provide structure but allow for participants to supply unique answers. Nine millennials were interviewed about their last conversations with a terminal loved one and the interviews were audio-recorded and transcribed. From this data, five common themes emerged between the Living and the Dying including: love, avoidance, messages about the past/future, everyday talk, and helping tasks. Studying the FC of millennials is important because their generation sees the world from its own unique perspective, and the best way to relate to a millennial engaging in FC is by providing examples of millennials whom have already engaged in FC in order to properly guide them.

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ACKNOWLEDGEMENTS

First and foremost, I'd like to thank Dr. Maureen Keeley for agreeing to supervise this thesis. It was a lot of work in a short amount of time, and she took that on with me and stuck with me even through all of the tough parts. I'd also like to thank: Dr. Michael Burns for helping me with my thesis presentation and for helping me achieving IRB approval. I'd probably still be emailing back and forth with the IRB board if it were not for your help. Monica Gonzales for taking time out of her day to help me edit my IRB application and work with me over the phone. Dr. Ron Haas and Dr. Heather Galloway for supporting me as I figured out the lengthy process of getting an IRB approved and for remaining flexible. Michelle Sotolongo for checking up on me to make sure everything was progressing and providing me with important phone numbers.

I'd also like to thank my parents for their unbridled support even when my thesis took over my life and I began to visit home less. Thank you for letting me call at weird hours to lament. I love you. Nik Crawford and the Crawford family for giving me a place to write in peace and for reminding me that I shouldn't stress over the things I cannot control. I also love you. Jamielee Jakubowski, Kathleen Terry, and Caroline Muller, and Ellie Connell for getting me out of the house once in a while. Much love to you four.

INTRODUCTION

“When you realize what he’s facing terrifies him, you kinda just don’t want to bring it up. You become so afraid of what will happen if he just gives up. So, I wanted him to think he’d have 15 more years. I wanted him to believe that lie because I was terrified of what would happen if he started not believing it.” (Grace, 19).*

Grace’s* hesitation in discussing her father’s immanent death reveals the idea that millennials do not have the experience of communicating at the end-of-life (EOL) with a loved one that is dying until it is thrust upon them, thus highlighting the need to explore their final conversations to understand how and what they communicate at the EOL. Final conversations “are all interactions, verbal and nonverbal, that an individual has with another who is terminally ill from between the moment of a terminal diagnosis to the point of death. FCs may involve only one conversation, but they can also be (and often are) a series of conversations” (Keeley & Generous, 2015, pg. 378). Final conversations have the potential to “strengthen relationships, reach closure, release old pain, and lead to shifts in identity and life direction for the Living” (Keeley & Yingling, 2007 pgs. 217-218). While these conversations are important, they often are challenging, especially if a person has never participated in communication at the EOL. If this is the case, then there is tremendous uncertainty about what to say, how to say it, and when to talk with a dying loved one (Keeley, 2007). The uncertainty that comes with communication at the EOL may be especially daunting for millennials (people between the ages of 18-37) that are

dealing with the death of a family member for the very first time. The reasons final conversations for millennials might be especially intimidating is because they need to overcome a number of fear-provoking challenges that include: a fear of death that is common in our culture (Keeley & Yingling, 2007), the loss of a loved one that will have a major impact on their lives (Keeley, 2007), and uncertainty about how to maneuver through a conversation about the impending death with a terminally ill loved one (Keeley, Generous, & Baldwin, 2014). This thesis investigates what final conversations look like for millennials and aims to answer the following questions: what is important for a millennial to communicate during FC, how do millennials communicate with the dying, and what obstacles do millennials face?

LITERATURE REVIEW

There is currently a substantial amount of literature on final conversations focusing on adults, children, and adolescents FC, (Keeley, 2004, Keeley, 2007, Keeley & Yingling, 2007, Generous & Keeley, 2014, Keeley, Generous, & Baldwin, 2014, Manusov & Keeley, 2015, Keeley, 2016) but none that have focused exclusively on that of a millennial's FC. It is important to study the final conversations of millennials, as most consider themselves excellent communicators, especially through the use of social media, but when it comes to communicating face-to-face in the midst of grief and fear millennials are inexperienced when face with navigating through conversations about death. Understanding the perspective of millennials at the EOL and how they communicate with loved ones at the EOL will increase understanding about FC and about this unique population. In addition, this knowledge is key to providing other millennials whom have not yet had to engage in FC with advice and guides, as well as give other generations an understanding of why and how millennials communicate about death in the way that they do.

FINAL CONVERSATIONS

The research existing in the past has primarily focused on the perspective of the terminally ill, rather than the surviving loved one (Keeley, 2007). For over a decade, Keeley and colleagues have been exploring the unique point of view of the person who continues to live after a loved one has passed. While it will always be important to focus on the communication needs of the terminally ill (hereafter referred to as the Dying), it

has become abundantly clear that it is equally important to examine and support the communication needs of their family members and other close loved ones (hereafter referred to as the Living) because they are the ones that will carry their FC with them after their loved one leaves (Yingling & Keeley, 2007).

During the precious time between terminal diagnosis and death, or during “mortal time” (McQuellon & Cowan, 2000), FC can occur. Previous research has shared examples from past participants to illustrate FC for people who have not experienced communicating with a dying loved one, acting as a guide for others to emulate (Keeley & Yingling, 2007; Keeley, 2007; Keeley, et. al. 2014). Most of the examples are from adults and children/adolescents and not specifically from emerging adults—millennials, that is the focus of this thesis. In the past and especially for millennials, Yingling and Keeley’s (2007) study stated that “Most people have little or no experience with death, so they are hesitant to talk for fear they will make things worse for the dying or themselves” (Yingling & Keeley, 2007, pg. 1) and this continues to be true. It is important that millennials understand how to get around the fear of these conversations, and see this “terminal time” (McQuellon & Cowen, 2000) with their loved ones as a gift that gives closure, acceptance, and personal growth through communication (Keeley, 2007).

FINAL CONVERSATION THEMES

Keeley (2007) identified several themes discussed by individuals during FC that include but are not limited to: love, identity of self and of the relationship, spirituality/religious faith everyday talk/ routine interactions, and difficult relationship issues (Keeley, 2007). Love and words of affirmation are the most common message given at the EOL (Keeley, 2007). Love is communicated through both words and nonverbal

actions, through messages of explicit statements of “I love you” as well as holding hands, kissing, spending time together, and a final look between the loved ones at the EOL (Keeley, 2007). The second most common messages given at the EOL are identity messages, which are often expressed either in regards to oneself or the relationship (Keeley, 2007). Self-identity is often formed from the relationships we are in, and confirming things with the dying like “strengths, gifts, and talents” that reveal perceptions about the Living can confirm one’s identity and the relationship’s identity (Keeley, 2007, pg. 237). The third most common messages are spiritual/religious messages, which are often used to find meaning when faced with death (Keeley, 2007). Declaring one’s faith to their dying loved one can create a spiritual connection between the Living and Dying and help ease any fears before the dying passes. The fourth most common message is everyday talk, which is communicated by continuing “mundane” or “routine” activities that would normally be carried out with the dying on a day-to-day basis (Keeley, 2007). This includes, but is not limited to, “shared meals, watching television together, listening to music, playing cards and other types of games, applying nail polish, brushing hair, and assisting with daily hygiene needs” (Keeley, 2007, pg. 241). Finally, the fifth most common message talked about at the EOL is difficult relationships issues, which are messages that bring up past interaction between the Dying and Living that may have been filled with criticism, defensiveness, guilt, manipulation, coldness, and even contempt. Often times, these conversations give the gift of reconciliation to the dying and the Living when they choose to talk about their past strained relationships and come to terms with one another. By engaging in these five

different types of conversations at the EOL, we are better able to grieve and process the death of a loved one (Keeley, 2007).

MODERN GRIEF

Psychologists and doctors refer to grief as a reaction to loss (Doyle, 1994). It's important to note that all people grieve differently, even in cases where people experience the same loss (Gilbert, 1996.) And although everyone reacts differently when grieving, common reactions that people associate with grief are: becoming quiet and contemplative, throwing oneself into a project or work, drinking more, or maybe ceasing communications with friends (Doyle, 1994). Even within families, grief and bereavement may not always manifest itself in the same way among individual family members (Gilbert, 1996). Despite all of the research on differing ways that a person might react to grief, Americans are still expected to hide their grief from the public eye and grieve alone (Keeley & Yingling, 2007) like a wounded animal. In actuality, grieving should be treated as a time to find a new normal in the unique way an individual needs in order to prolong their personal grieving process (Attig, 1991 as cited in Gilbert, 1996).

In the case of knowing that death is imminent for a person, grief actually begins when one first learns of a terminal diagnosis (Doyle, 1994). Thanks to "medical advancements in the diagnosis and treatment of cancer and other degenerative diseases, we can anticipate "dying time" more accurately than before," (Keeley & Yingling, 2007 pg. 1). With a more accurate idea of when a terminally ill person will pass, the time allotted to engage in FC has lengthened. This crucial time period between death and

terminal diagnosis is when FC can be utilized to help deal with the grieving process with the assistance of the Dying (Keeley & Yingling, 2007).

Specifically, when grieving begins before the death of the loved one, the one person a grieving relative may want to talk to about their feelings with is the very person that's dying, and that can feel impossible and awkward (Doyle, 1994). However, talking about death with the dying is an important part of the grieving process, and can provide much-needed closure to the relative being left behind (Keeley, 2007).

MILLENNIALS AND THINKING ABOUT DEATH

The Millennial generation has been regarded at the most overprotected generation of all time (Cecere, 2016). Because of the extra attention that many received from their parents, they are also generally thought of by older generations as “spoiled brats” (Howe and Staruss, 2000, as cited in Cecere, 2016). This belief may also stem from the fact that millennials are delaying adulthood (marriage, parenthood, etc.) into their late twenties, rather than preparing to become an adult when they first emerge from their teenage years (Arnett, 2000, 2007, as cited in Cecere, 2016), which may be perceived as lazy.

Millennials have also been taught that everything they could possibly want to experience is within reach (Twenge, 2006, 2009, as cited in Cecere, 2016), and therefore they may not feel time pressured into finding a partner and starting a family right into adulthood. Beyond becoming an adult, millennials have not felt societal pressure to think and prepare for death (Deibler, 2016), whether it is their own death or their loved one's. In fact, they have most likely felt the opposite, as the topic of death is a taboo in American Society (Keeley & Yingling, 2007).

Due to the lack of discussion about death, adverse effects are created and burdened on the individuals who have been affected by death, dying, and bereavement (Abba, 2016). Americans are “taught to deny death, to ignore grief, to avoid talking about death, and to mourn, in private” (Keeley & Yingling, 2007, pg. 3). And with the suppression of communicating about death, it becomes an uncomfortable topic to discuss when the time forcibly arises. Death should be normalized and not ignored.

Not many people are eager to discuss death (Keeley & Yingling, 2007), so explaining what death is to a child may be perceived as daunting and uncomfortable (Keeley & Generous, 2014). However, it is important for child’s development to not only understand what death is, but be allowed to openly communicate with the dying before they pass (Keeley & Generous, 2014). And even with a death experience and an explanation, if not done properly, explaining the finality of death to a child, as children under the age of three do not understand that aspect of it (Keeley, Generous, Baldwin, 2015), may stunt a child’s ability to rationalize and accept the inevitability and finality of death in their later life (Knight, Elfenbein, Capozzi, 2000).

A 2000 study involving older millennials by Knight, Elfenbein, and Capozzi showed that a person was more likely to fear death later in life if a relative died and their parents explained death to them, rather than a pet death, in which parents were reported to be able to explain death better when the explanation was based on the passing of a non-human. One of the conclusions by the researchers regarding this discovery is that talking about the death of a pet was “nonthreatening” and easier for parents to explain (Knight, Elfenbein, Capozzi, 2000) than the taboo topic of human death (Abba, 2016). Parents may find the subject, in the light of a human death, harder to talk about with their

children. Another cause of the poor explanation was that the grief-ridden parent's overwhelming emotions after losing a loved one got in the way of their ability to give a proper explanation (Knight, et al 2000). This inability to push aside emotions could also be amplified if the parents were taking care of the dying loved one (Doyle, 1994). In addition, people that are responsible for loved ones' substantial care needs at the EOL often report symptoms of depression and state that caring for their terminally ill loved one interfered with family or personal life (Emmanuel et al., 2000, as cited in Abba, 2016). Both of these issues complicate individuals' abilities to effectively communicate with their children, adolescents, and emerging adult children about EOL. Knight, Elfenbein, and Capozzi's research concluded that many older millennials now fear death if they were given an inadequate explanation to what death is during their childhood, while children that were exposed to communication about death and dying pertaining to a pet are better prepared and less fearful about EOL. Being an "overprotected" generation (Cecere, 2016), many of the younger millennials may have not have had adequate conversation concerning death and communication at the EOL to neutralize their fears about dying.

In order to offer proper FC guidance to the living, models for communicating with the dying are important information to share so that people do not feel like they are left alone to try and figure out what to say and how to say it (Keeley, 2007). Communication at the EOL has become a public health issue in the UK, as they have realized the benefit in encouraging FC talk to help individuals in coping with imminent loss (Abba, 2016). Death impacts the public's mental and physical health (Abba, 2016). People believe that the subject of death and dying is not discussed enough and they would like for that to

change (Abba, 2016). In a Dying Matters-commissioned national study done in 2012, “78% of respondents agreed with the statement: “If people in Britain felt more comfortable discussing dying, death and bereavement, it would be easier to get end of life wishes met”” (Abba, 2016, pg. 18-19). Similar studies should be done in the USA to gauge the public’s feelings toward neutralizing the death taboo. While organizations such as hospice are actively trying to help the public feel more comfortable when talking openly about death and dying, communication scholars are also trying to raise awareness about how to effectively communicate with a dying loved one (Yingling & Keeley, 2007). This would greatly benefit the population’s ability to have meaningful conversations toward the EOL.

On top of the death taboo negatively affecting their attitudes toward death, millennials, unlike the previous generations that lived through large-scale wars and drafts (Deibler, 2016), are not thinking about death as if it were in the short-term. Instead, Millennials “are looking forward to finishing college, getting married, buying a house, having kids and advancing in their careers. Moreover, at this stage in their lives, millennials tend to have a sense of invincibility that causes them to ignore the risk of fatal accidents” (Deibler, 2016, pg. 30). And since more millennials are prolonging marriage, buying a house, having kids, etc. (Cecere, 2016), the possibility of death feels infinitely farther away without having yet passed these huge adulthood milestones. This also affects millennials’ likeliness toward thinking and communicating about death.

Millennials think and act towards communication in very different ways than previous generations (Cecere, 2016). Millennials are unique in that they are the first generation to grow up with technology, which has changed the way they communicate in

their personal relationships (Cecere, 2016). “Each generation brings forward distinctive beliefs, ideas, and attitudes,” (Cecere, 2017, pg. 8) thus, each generation perceives the world around them through differing lenses (Cecere, 2017).

MILLENNIALS AND COMMUNICATING THROUGH TECHNOLOGY

Millennials have a unique way in which they perceive the world around them and communicate in different ways than previous generations, which is driven by the fact that they grew up with technology. With social media at their fingertips, they are granted the ability to keep in contact with distant friends and relatives on digital social platforms, and have an overall positive attitude about utilizing technology for communicating (Cecere, 2017).

“Adolescents have incorporated electronically based vehicles of communication into all aspects of their lives. These include email, texting, Tweeting, Instant Messaging, sharing music, blogging, and participating in Social Network Sites such as Facebook” (Read, Shah, S-O’brian, Woolcott, 2012, pg. 491). Because of these social media platforms, millennials have not necessarily ever had to say goodbye to a person unless they make the choice to stop communicating. And even when they do decide to end communication with a person, they are still able to keep up with said person’s life, if they so choose, by “following” the activities that someone may post on social media networks. Even then, they can always reach out and begin communicating with a person they haven’t talked to in a long time with ease, which isn’t the case if the person is deceased. With death, there is an abrupt and often unsatisfying end to communicating with a person loved by a millennial, which can often be their first instance of experiencing the finality of the word “end.” And with the infinite bounds of technology at their disposal, if they

haven't yet experienced a death before early adulthood, they may have not ever had to have a final conversation with even an old friend from high school.

Final Conversations are important at the EOL for both the Dying and the Living. Millennials provide an important population to explore at the EOL because they have not been explicitly studied as of yet, and because their parents overprotected them from real but challenging realities inherent in life (Cecere, 2016). In addition, millennials communication is unique from previous generations because of their keen relationship with social media and technology. Based on these arguments, the following research question guided this descriptive inquiry:

RQ1: What are the verbal and nonverbal messages millennials report were exchanged during final conversations with the dying?

METHODS

This study utilized a qualitative approach to collecting FC stories from millennials. Focusing specifically on the point of view of millennials whom knew a loved one was dying, a structured nine-question interview process was employed to prompt participants to recollect and re-tell their FC (verbal and nonverbal) at the EOL with a loved one from time of diagnosis until death.

PARTICIPANTS

Following approval from the University IRB, participants were recruited from a purposive sampling procedure, in this case a sampling of individuals' who have experienced one or more FC with a loved ones were recruited from a Southern University communication class and from a snowball sampling technique. This procedure was used to ensure an information rich sample, which is necessary when exploring specific and often times difficult to find populations (Devers & Frankel, 2000). Participants had to meet three criteria to participate in the study: (a) have had one or more FC (verbal and/or nonverbal interactions) with a loved one, with both participants' knowledge and understanding that one of them was dying; (b) have a clear recollection of the FC interaction(s) which took place any time between the diagnosis of "terminal amount of time to live" and the actual death, and (c) were a part of the millennial population (18-37).

The sample was composed of nine participants ($n = 9$) whom were found to fall under the three study requirements of being a millennial (age 18 to 37), both participants'

knew that the Dying had a terminal illness, and had a clear recognition of their FC interactions(s). Specifically, the researcher used several ways in which to collect eligible participants for this study. First, a convenience sampling method was used, as the thesis supervisor asked students in one of her communication classes for participants. From there, one person was discerned as eligible to participate in this study. Second, a purposive sampling method was used, as the researcher asked millennial friends if they had any experience with a terminal loved one. From that, five people were discerned to be eligible to participate. Third, a snowball sampling method was used, and participants were asked to suggest friends that may have participated in FC. From that, three people were discerned to be eligible to participate. Following approval from the IRB board, the researcher collected the emails of participants and sent out the approved email script and consent form. Four participants identified as male ($n = 4$) and five participants identified as female ($n = 5$). The duration between the death of a loved one and interview ranged from two weeks to 6 years. Only one participant's loved one was currently still living during the time of the interview. The age range was from 19 to 26, with a seven-year difference between the minimum age and the maximum age, and the average of all the participant's ages was 22.

PROCEDURES

The interviews for this research took place over the span of a month. After the IRB approved the email script and consent form, they were sent to participant's emails, and then participants were re-contacted by the researcher to schedule a time to interview. Before the interview began, each participant was handed a hard copy of the consent form to re-read and sign, to which they were allowed to decide if they wanted theirs and their

loved one's first names used in the reported research or if they preferred pseudonyms. Participants with pseudonyms were marked in this thesis with an asterisk (*). Finally, consent to audio-record their interviews in order to later transcribe and code was obtained. The interviews lasted from 8-24 minutes and depended on how much the participant had to say when prompted with the following nine open-ended questions:

1. Can you tell me a story about a time that you talked with (_____) before they passed that was important to you?
2. Why was (paraphrase their answer) important to you?
3. Who initiated the talking?
4. Is there anything you didn't talk about? If so, what?
5. Why didn't you talk about (paraphrase their answer)?
6. Is there anything that you wish you said but didn't? If so, what?
7. What sorts of nonverbal experiences or actions did you experience with your loved one before they passed?
8. What did each of the nonverbal experiences mean to you?
9. Is there anything else that you want to add about your communication with (_____) that you didn't mention previously?

This study is a replication of Keeley's (2007) study that utilized interviews. This study employed a standard, open-ended interview technique, as to provide structure but still allow participants room to respond with unique answers. The interviews were also done one-on-one (with only the researcher and the participant) to create a trusting and safe environment to openly recollect and reflect past FC and provide anonymity for those whom decided they did not want to be identified in the research report. The data resulted in 43 transcribed pages of data.

RESULTS

From the transcriptions of the interviews, six themes were discerned to have emerged frequently throughout the nine interviews. These emerging themes are: love, avoidance, messages about the future/messages about the past, everyday talk, and helping tasks. These themes are in order of most common, respectively. The two most common themes were love and avoidance, which appeared in all nine interviews.

LOVE

Love, as stated previously, was the first most common theme that emerged in all nine interviews. The data suggests that millennials often use words and nonverbal expressions of love to affirm their connection with the terminal during FC at the EOL. Words of affirmation, touching, and hugging were all found to be important to the millennial participants when engaging in FC, but nonverbal expressions of touching and hugging were discerned to be more common than words of affirmation, with only a few reported instances of verbal communication when millennial participants reported their FC. Katie was one of those few, and made a point to verbally tell her grandmother, Sophie*, that she loved her every day.

“I said to her every time that I saw her that I loved her. And that was pretty much all I felt like I really needed to say to her. Just make sure that she knew that I loved her no matter what. And I said that almost every day.” (Katie, 23)

It was important to Katie that Sophie* heard her say she loved her every day at the EOL. It was how she preferred to show affection, and she derived great meaning from being able to vocalize her love for Sophie*. Like Katie, Christopher would also give his grandmother, Effie, words of affirmation, but he reported that a large frequency was not necessary in their relationship.

“I don’t know, maybe some people would want to have a relationship where you just say I love you like a ton. We didn’t say I love you verbally a lot, but you know, every birthday, Mother’s Day, Christmas card, would always be like I love you so much. And I feel like that was fine. I don’t feel that it should have been more than that.” (Christopher, 26)

Christopher is Nik’s older brother, but they both had different experiences with being affectionate with their grandmother, Effie, during FC. Nik, like the majority of millennials interviewed, mainly utilized nonverbal communication and preferred to show his love for Effie, rather than verbalize it. He used hugging as a greeting to her, especially when they hadn’t seen each other in a while.

“We hugged when we saw each other and like if it was a greeting. Like if I wasn’t staying at the house for that evening, or if we were just seeing each other while I was away from college, then yeah. It would start with a hug and end with a hug.” (Nik, 23)

Nik, when hugging Effie, would often take extra care to be gentle with her. He understood Effie’s fragility and showed his love by taking extra care to not squeeze her too tightly when he showed his deep, familial love through an embrace.

“Hugging an old person is different than hugging a young person. You gotta be a lot more careful. It’s like a fake hug. Not in the meaning or emotional sense, but like you’re more just putting your hands in the area and like applying pressure maybe. And like, a small amount of pressure on the hands maybe, but not the actual forearms or anything. So they were a lot more delicate hugs. Because I was like, I want to be careful here because you’re 92 years old. [But] it meant the same as like a hug to my mom. Or a hug to any other family member.” (Nik, 23)

Nik, in his love for Effie, was fully aware of her fragility and made sure he never hurt her when showing affection. Another example of utilizing touch to communicate love nonverbally is when Annie would hug her grandfather, Jack. Annie, although she would also verbally say she loved Jack, prefers to hug people when she wants to show affection. Although he wasn’t big on hugs, Jack would still allow Annie and her family to hug him. Annie reports that this was because Jack understood that it was how she liked to show love and affection not just to him, but to all of her loved ones.

“I like words of affirmation as well as touch, I’m a very big toucher. Like I love hugs, I love... like I try and make a point to like, being a professional now, like now I have to ask people if I can hug them before, but really I would just hug everybody. But so I think like my family, because we all love each other, and we show each other it physically and stuff, so it’s like fun knowing that he... like granny, and granddaddy started that, you know? But they

weren't very big touchers with their children. So it's like, my mom has 3 brothers, and so it's funny because like, granny and grandpa didn't touch, so I'm like this huge toucher, and my mom's a toucher, too, and so it's funny seeing that grandpas just like, even throughout his life, just like ah whatever you can touch me but whatever. It didn't mean a lot to him, but he knew it meant a lot to us, so." (Annie, 23)

Although Annie talked about hugging Jack in broad terms, Grace* recalls an exact moment of physical intimacy between her and her family right after her father, Samuel*, was first taken to the hospital for diagnosis. Having used her parent's bed as a center of family bonding for years, Grace* and her siblings all chose to show their love and support to Samuel* by piling on the bed with him.

"One of the biggest physical moments we had was the first time we came back from the hospital. We still weren't really sure what was going on. I mean, it was a tumor, it was all of this stuff, but they weren't giving us a lot of information. Cause you know, doctors and law-suits. They get scared. Me and all my siblings just piled on the bed with him and we were all trying so hard not to be sad. We were all trying so hard to show him that we were brave and we weren't scared. And we just didn't let go of him. We just sat there piled on the bed with him. And you know, it was kind of a big moment because they've had that bed for years, and we always

wrestled, had big forts, and we had dog piles, and it was this place where we just loved each other.” (Grace, 19)*

Coming back to a familiar place helped Grace* and Samuel* throughout the diagnostic process and was one of the first instances of their FC. Although piling on a bed with her siblings and father was a familiar action to Grace*, hugging and physical touch may also occur at the EOL even though it is not normally an action that takes place often. Jamielee’s grandmother, Sue, was not a grandmother that hugged Jamielee excessively. So at the EOL, when it became apparent that Sue would not last much longer, Jamielee was able to share a meaningful embrace with her grandmother that helped her realize that Sue had an expiration date.

“I do remember one hug... actually, this was before my last time seeing her, this was my second to last time seeing her. It was very possible that it could have been my last time, so I remember specifically hugging her on top of a parking garage after a cruise we went on, and I hugged her and in my mind I was just thinking about how this could possibly be my last time hugging her. Which, luckily that wasn’t, but that... it became very real to me then.”
(Jamielee, 21)

While hugging was important part of FC to many of the millennial participants, touching FC also manifested in hand-holding at the EOL. Often times, as Nik previously stated, a person at the EOL is fragile and great care must be taken to not injure them from a hug. Hand-holding was often common during FC when a loved one was too weak to get out of bed or a wheelchair. Katie’s grandmother, Sophie*, was bed-ridden and

wheelchair-bound, so their FC often involved holding hands to show their love to each other. As shown previously, Katie liked to verbalize her love through words of affirmation and declaring her love everyday to Sophie*, but she also greatly appreciated holding Sophie's* hand when they wanted to be affectionate.

“She took to just holding my hand a lot... Yeah, and she would just hold my hand a lot, like I would sit down next to her and she would just grab my hand. She didn't have a lot of strength in it because the stroke had done some damage to her arm, but she would just kinda grasp my hand and hold it or like pat me on the leg or something.” (Katie, 23)

Nico, whose grandmother, Otelia, was also bed-ridden, took to holding Otelia's hand when he wanted to show his affection for her. He mused that it was an important action for him and his grandmother, as he held unconditional love for her, and he showed it nonverbally during their FC. A kiss on the cheek was also often an action that took place as a greeting for them, which was not something that emerged in the other eight interviews, but held significance to Nico.

“Just like holding her hand...and you know anytime we greeted each other, said goodbye, it was always a kiss on the cheek. And, yeah, just like holding her arm, holding her hand.” (Nico, 23)

All nine millennial participants engaged in the theme of love, both verbally and nonverbally, during their FC with their loved on at the EOL. Nonverbal FC however was the most common way that millennial participants communicated affection with the dying, which gives insight into how millennials prefer to communicate love at the EOL.

AVOIDANCE

The theme of avoidance was the second theme that emerged most frequently out of the five themes discerned by the researcher, also appearing in all nine of the interviews. While avoidance sometimes manifested in evading politics and religious talks, avoidance that most millennial participants engaged in was often to escape conversations that alluded to or pertained to the finality of death. For example, John* felt that he was unable to give a final goodbye when given the opportunity to say goodbye to his grandmother, Nancy*, who was dying of a brain tumor, so he avoided the situation altogether:

“Right before she passed away, like the days leading up to it, it was kind of obvious that she was about to die and the last time I saw her I was unaware that it was the last time. And so, when she was about to die, I had the opportunity to like, go say bye and stuff. But, because I was young, it was kind of a situation I was not comfortable addressing head on, so I didn’t.” (John, 21)*

Another instance of avoiding the situation of impending death altogether is when Kathleen had the opportunity to visit her friend’s dying mother, Sara, whom had liver cancer and whom Kathleen had grown up with, but Kathleen chose to avoid the situation. Sara had moved to the same town that Kathleen goes to college, but Kathleen felt some reservations about visiting Sara while she was in a cancer-ridden state, and so she felt too uncomfortable to visit Sara at the EOL.

“I guess I was just scared. I didn’t want to see her because she had gotten so skinny... well she got really skinny everywhere except her stomach because her stomach was really bloated and she just didn’t look like she was and I was scared that if I saw her like that it would change how I remembered her. And I guess I was just kinda selfish and didn’t wanna have to face the actual truth that she probably wasn’t going to make it. Because I know that my best friend is her daughter and she always texted me and always talked to me about it and I’d always be like, “No she’s gonna get better, blah blah blah.” And I think if I had seen Mrs. Sara looking how she had looked, then I wouldn’t have been able to tell Megan that I thought she was going to get better cause I wouldn’t be able to honestly tell her like, “No, she’s gonna get better.” I’d be like, “No...she’s gonna die.” (Kathleen, 21)

In John* and Kathleen’s case, because they lived apart from their loved one, they were able to avoid FC at the EOL. Many times, physical and direct avoidance is impossible, like when the terminal loved one lives in the same house as the millennial. However, it is still possible to avoid the topic of death, like when Grace* and her father, Samuel*, were faced with continuing to deny or finally accept his terminal brain cancer and the fact that he didn’t have long to live.

“I mean, at fist when my dad got sick he refused to believe that he was sick. He kept promising me that he had 15 more years, that he was gonna be around, that he was gonna walk me down the isle,

all those things... me and my dad both kinda had the same kinda way of dealing with it, which was we both knew it was happening, but we were gonna ignore it. We were gonna pretend like it wasn't happening." (Grace*, 19)

Because Grace* and Samuel* had ignored his terminal illness for so long, it was hard for them to address it once Grace's* avoidance began escalating and started leaking into her other relationships. It was Grace's* mother that finally mediated and encouraged the both of them to engage in FC about Samuel's* impending death from terminal brain cancer.

"And my mom was kinda the one that was like, "No you have to, you have to talk." I think the biggest push was when I stopped going to church. I refused to go to church. Down right refused. I wouldn't talk to anyone at church. I didn't, just wouldn't. I refused to talk to anyone. And that's kinda when my mom was saying to my dad, like, "You have to talk to talk to her. You can't just pretend it isn't happening. There are so many things going on. If she has to drive you one more time to the ER, like, she knows what's going on." So, she kinda had to force us to start talking." (Grace*, 19)

However, even with the intervention that Grace's* mom provided, Grace* and Samuel * were only able to have one FC about his death and what to expect in a future without her father. Grace's* interview was the only interview in which the terminal loved one was still alive at the time of interview, and with Samuel's* brain tumor causing him

to lose most of his ability to speak, Grace* and he are now avoiding deep FC discussions altogether.

“He has a lot of problems talking. So he doesn’t like to. And then of course, with everything going on, I just... I don’t talk to him as much. You’d think with the experience and everything that’s we’d be closer than ever, but when I look at him, it’s hard to see my dad. So we don’t have a lot of conversations anymore. We don’t sit around eating oreos and drinking milk. We’ve lost those connections, we’ve lost that communication. And I could try to have those conversations with him now, I could, but I don’t think he would really know what to say. So, communication is not good. You keep it to the simple subjects. You keep it to what I’m doing, you keep it to what he’s doing. “How have you been?” You know, kind of like those family members you see at reunions that like you know you’re related, but you have no idea how. It’s... yeah, it’s kinda turned into that.” (Grace, 19)*

While both parties, the Living and the Dying, in Grace’s* situation avoided the topic of death, sometimes it is only one party that will evade situations in which death is brought up. Jamielee is very uncomfortable about talking about death while her grandmother, Sue who was dying of lymph node cancer, was able to talk about her impending death with ease, much to Jamielee’s distress.

“Yeah, she had cancer in her lymph nodes. I just didn’t like talking about that. And so, I would avoid it when the conversation would

seem to steer towards her death. She was very comfortable with talking about death, but I'm not. And so, if she would bring up her death, or even just her cancer, I would just kind of try to divert the conversation to something else, because it freaked me out, but she was very comfortable with it." (Jamielee, 21)

Jamielee then reveals that it was not just death that freaked her out, but also the fact that Sue was so comfortable with talking about her death that frightened Jamielee, and she believes this was another reason she couldn't bring herself to let the topic of death continue when it arose.

"Well, death really does freak me out. And so, it also made me uncomfortable with how comfortable she was with it, because she doesn't believe in anything beyond life, and I do, and so it was just, it was very shocking to me, because even though I do believe in something beyond my life, I'm still terrified of it. And so, I couldn't comprehend how she was so... it was so normal to her, if that makes sense. You know?" (Jamielee, 21)

Jamielee then later mused that, if given another chance, she might have let FC about death continue in hopes to quell her own fears about death by learning how Sue was able to accept it. However, now it is too late.

"I think I wish... I know that it freaked me out, but now that I'm thinking about it, it would have been interesting to talk about why she was so comfortable with it. But, I feel like the conversation would have freaked me out too much and I would have to just stop

it. But I feel like if I could speak to her one more time, I might ask that if the conversation came to it and got that deep enough for that. I wouldn't just flat out be like, "Hey, so why are you so cool with dying?" But, I feel like would just... I would ask her what brought her to this comfort so that one day I can find that comfort, because I still don't have that." (Jamielee, 21)

Even though these examples show avoidance out of fear or uncertainty or awkward feelings, avoiding death FC at the EOL does not always have to have a negative connotation surrounding it. Nik would often be subjected to his grandmother's, Effie's, light-hearted banter about her impending death and would avoid commenting on it due to her light-heartedness when talking about it. He wouldn't steer the conversation away, like Jamielee, but he also didn't feel like it was appropriate to comment.

"I definitely did avoid all sorts of responses or conversations talking about her "crossing the River Styx." Not because they were sad, again she was always like, "Welp." In that sort of like, I don't know if you want to call it, "faux-cheery?" Or, you know, it was genuinely cheery, but it was definitely her way of coping with it, I assume. I would just smile and laugh though because I don't think that's too much of a unique thing. But I was never like, "Yep. And we'll be sad to see you leave." You know? Because, none of that necessarily felt appropriate." (Nik, 23)

Nik, like Effie, copes with serious issues by making jokes about them. In this case, when Effie would joke about her death, Nik didn't feel that it was necessarily

appropriate to join in on her light-heartedness of the subject. And so, when Effie would speak of her impending death lightly, he chose to avoid commenting and would, instead, respond nonverbally by smiling and giving Effie a complimentary chuckle.

“So like my... my natural instinct of, again, like a larger serious issue, is to make light of it. But I only feel comfortable acting on that instinct when it’s like, my issue? Like I’m not gonna make light of someone else’s big issue. Like I’m not going to say, “Oh you have cancer? Well, boy you’ve been so fun to be around.” You know?” (Nik, 23)

While the theme of death was the most common FC topic reportedly avoided by millennial participants, other topics like religion and politics were also avoided at the EOL in an effort to try and create a positive environment for the dying. An example of political avoidance is when Katie and her family tried to hide the fact that Donald Trump had won the presidential election from Sophie*, whom was dying after a stroke severely damaged her brain.

“We tried for a while to hide the fact that Donald Trump had won the election. We had intentionally wanted her, cause we were pretty sure she wasn’t going to last for too much longer, we wanted her to pass thinking that she had seen the first female president. She was 92, and she had been born like 5 years after suffrage for women. She was so excited to have a female president, so we had wanted her to pass thinking she had seen a female president elected. That didn’t wind up happening, but I mean, I

guess kind of the stroke was a gift in that sense because she wasn't totally aware that he had won the election.” (Katie, 23)

In the end, as Katie said, Sophie* found out about the results of the election, but was, to the joy of her family, unable to completely grasp it. Another example of avoidance was reported by Nico, whom avoided engaging in FC about his and his grandmother's differing religious views. Nico does not believe in a higher power, while his grandmother, Otelia, was a devout catholic. In order to avoid a conversation that he decided would not end up benefitting him, Nico decided to never challenge Otelia when she spoke about her religious beliefs.

“Well, growing up, she was just a stout catholic, and my father and my mother put me through like, this section of baptism, so it was already like a little different in our beliefs and practices. And then when I got to be around 13 or 14, I stepped away from the church and just really didn't believe in that anymore. And I always knew not to talk about that with her. I didn't want to rub her the wrong way because of how religious she was.” (Nico, 23)

Nico took great care in making sure he never challenged Otelia's beliefs, even going so far as to not comment on a few underlying racist comments she made, because she, as his provider, had the final opinion on most things in his family.

“And we also didn't really talk about like, social issues. I think she might have been, and I hate to talk this way about my grandmother, but you know, she was a little uh... she had moments of underlying racism. And that's like, you know. I guess just with

the generation that she came from. Not to excuse her, but I guess I can sympathize with where she came from. And so, yeah. We just kind of avoided muddy talk like that. It was just kind of surface level. Yeah, I don't know. I knew not to argue with her. She was a matriarch.” (Nico, 23)

Nico goes on to further explain why he chose not to ever engage her in debate because, he discerns, he was not raised to fight with someone who provides for him. Because of his upbringing, he never engaged in FC that addressed their differing religious and social views.

“Yeah, again, it's definitely the way I was raised; to not bite the hand that feeds you. You know, she helped my parents out quite a bit in you know, buying us school supplies when we were younger, or giving me money to pay for rent here in college. And so, you know, I didn't deserve any of that money. I didn't deserve her financial support. And so I couldn't like tell her... yeah, I don't know, it just wouldn't have made sense for me to do that. I couldn't go against her like that. I wouldn't want to, anyway.” (Nico, 23)

All nine millennial participants engaged in some form of avoidance at the EOL, from avoiding politics like Katie, to avoiding any form of FC involving death like Jamielee. Discerning this emerging theme in FC engaged by millennials is important in understanding and aiding millennials' future interactions at the EOL. While some topic avoidance helped individuals in their FC, like Nico and Nik, most of the time it hindered

relationships at the EOL, and caused surviving millennials to later regret missed opportunities that could have aided closure.

MESSAGES ABOUT THE PAST/FUTURE

The second most common theme that emerged from the data were messages about the future and messages about the past, which were discerned to be in eight out of nine participant's FC at the EOL. Reminiscing about the past was very important to millennial participants, as it affirmed their relationship with the dying as well as allowed them to learn things they didn't know about the dying's life before they had known them. Katie had the unique opportunity to write Sophie's* obituary. From this experience with her grandmother, Katie was able to learn about the entirety of Sophie's* life. Sophie*, who was suffering from a stroke, was not always completely present mentally, and this interaction was a rare moment where Katie was able to see and talk to pre-stroke Sophie*.

“One moment that was actually kind of special was she asked me to write her obituary so she kinda told me her life story and I just wrote it down exactly as was, as she said it. And that was one of the longest periods where she was, for the most part, there and present in that moment. She just told me everything. She said all of these really funny things about like my grandpa and the first time that she saw him and she was like, “He was the most handsome piece of mankind” and she never would have said that before the stroke, but little gems like that came out as she was telling the story, and she was like, when he proposed, they had been dating

for only two months, and it was during WWII and he was on leave, and so he wanted to propose before he went back and she was like, “Well I just said yes as quick as he could before he changed his mind and got away.” And so, just hearing little things like that was really meaningful, and some of it my mom had never heard before and same for my uncle, and so hearing things like that was really neat. And that was one of the longest conversations we had after she had her stroke, and that was pretty special and fun.”

(Katie, 23)

While Katie’s FC about the past occurred in one instance, many times past FC occurs over a longer period of time during the EOL. Jamielee’s grandmother, Sue, often would tell her stories about her life, which became a norm for them even after her terminal diagnosis. Jamielee admired her grandmother because of all of the traveling she did and enjoyed hearing about her wacky tails, which were light-hearted moments that they shared together.

“Her favorite thing to talk about was just her life, which was very interesting to me. She always had a story for everything, and always had crazy stories. My favorite thing she ever told me was she had four men on three continents. That’s my favorite thing ever. My grandma was a badass.” (Jamielee, 21)

With her stories, Sue gave Jamielee someone to admire and attempt to emulate in her future. Jamielee has now started traveling because of Sue, and now has a greater desire to see the world, which is a gift that Jamielee received from her FC with Sue.

Annie and her grandfather, Jack, would also often engage in messages about the past.

Annie liked to hear his stories because it made her feel closer to him. Once she noticed that he had begun to decline, she knew she needed to take action to preserve her grandfather's past.

"Kinda toward the end when I knew that he clearly was kind of going down hill and stuff, I would try to ask him about his parents and stuff and then I'd like secretly video-tape him. And so those were like fun conversations." (Annie, 23)

Annie then states:

"Knowing that he was fixing to pass, I wanted to get as much information out of him as I could." (Annie, 23)

Annie was also reminded of Jack's past through nonverbal interactions with him. Jack would often try and get out of his hospital bed, and they would have to fight with him to lie back down. This reminded Annie of his strong-willed determination from when he used to work long hours outside doing physical labor. He built a concrete business from the ground up, and seeing his will to get up and keep moving at the EOL made Annie recall how he was before he became ill.

"Like he did not want to stay there, you know because he had been active his whole life and stuff, so you know, he was like literally trying to climb out of his bed. Like his really frail, scrawny legs, because you know, they get so tiny, he was trying to like not heave them over, but catapult them over because he was tryna get out of the bed and so much. And it was funny because like the whole time

we would like fight, we were like fighting him to stay in the bed because like you know he hadn't used his muscles in a while, so even if he was able to get out of the bed, where are you gonna go, you know? And so that was a lighter and funnier moment. Like he kept his determination until the end.” (Annie, 23)

The past can be light-hearted or the past can be heavy. For Annie, remembering Jack's past was light-hearted. For John*, when his grandmother, Nancy*, would talk about her abusive past, it was a darker subject matter. However, he was often amazed at the person she had become despite of it. The gift that came from his newfound awareness about the abuse that she survived gave him was empathy for people who had been abused, and he carries that with him to this day.

“One time she told me about her kind of abusive past as a child. And she was kind of the like, kindest, greatest, nicest person you would ever meet. And so knowing the background and like seeing how that kind of like morphed her into the good-hearted person she was really interesting. I think kind of like gave me an idea of sympathy of people in those types of situations.” (John, 21)*

While messages about the past were a common interaction used to inform millennials about a time period that they were not a part of, messages about the future were also utilized during FC to include the dying in a future that they may not be apart of. Christopher had a talk with Effie during a hospital visit in which he announced plans to marry his current girlfriend. He knew that Effie might not last until then, as she was 92

and quickly declining. He wanted to include her in a future she may not be apart of, and so he explained what his goals for the future were.

“We hung out and talked about...like I made it a point to tell her everything in my friends’ lives, but also I told her that [my girlfriend] and I were thinking of getting married one day and I think that was my way of trying to let her know how the story goes, like I had a feeling she wouldn’t make it to the wedding and that wasn’t in the direct future so, I don’t know. I’m glad I got to say that stuff.” (Christopher, 26)

Another example of messages about the future is when Nico talked with his grandmother, Otelia, about his desire to not get married in his imminent future. Otelia had always wanted and expected Nico and his brother and cousin to get married by their early twenties and have children, since that was what she had done, and accomplishing these goals was in her definition of success. However, Nico did not foresee himself getting married anytime while she was alive, and attempted to console her.

“She was asking me about like, my future. My potential wife, my potential children, and that something she always wanted from us, like there are three grand-boys and she never had a granddaughter, so she was always wanting us to get married and have a daughter and hopefully see the great grandchildren. I guess it was just like her expectation for us at this age of early 20s for all three of the grand-boys. Because we were all... two of us were in school, one of us was working. So uh, we just weren’t in any

situation to have a family of our own, it just wasn't feasible, it didn't make any sense. So, having to tell her that like, it's just not gonna happen, I don't know. That was pretty tough. She got to meet my girlfriend, she got to meet my cousin's girlfriend, she got to see pictures of my brother's girlfriend, and so she was happy that we were all like, happy with other people. Uhm, yeah I don't know. That was a big thing growing up was her getting to see us get married, and she didn't even get to see me graduate, and she won't see me graduate, and that's a step before in the sequence of events." (Nico, 23)

Although it was hard for Nico to admit to his grandmother that he would not be getting married during her lifetime, the gift he received from revealing that to his grandmother gave him a greater sense of himself and confirmation that his chosen life path was the correct one.

"I suppose it just validated myself, or the fact that I needed to take steps to attaining, or getting certain places in my life. I mean I wasn't ready for this stage. I was aware of that, and I guess just explaining that to someone else reassured myself of my... I wouldn't say immaturity, but just lack of readiness. So, you know, in that sense it was... yeah, I don't know, I have a life to live before I get settled down and I just gotta keep that in mind, you know."
(Nico, 23)

Eight out of nine millennial participants engaged in messages about the future/past at the EOL, from writing obituaries, like Katie, to including a loved one in a future they may not be apart of, like Christopher. Discerning this emerging theme in FC engaged by millennials is important in understanding and aiding millennials' future interactions at the EOL. Many times, talking about the past and the future gave millennials everlasting gifts, like John* and Nico. This enlightens us in how engaging in this particular kind of FC may be helpful to a millennial that is just starting to engage with the dying and may need some guidance on what types of interactions may be most helpful to them.

EVERYDAY TALK

The third most common theme that emerged during millennial participant's FC was everyday talk, which appeared in seven out of nine of the millennial participant's interviews. Everyday talk is all of the conversations that involve conversation topics that normally arise in a relationship, like how someone's day was, how the weather is, how school is going, etc. Engaging in everyday talk during the EOL creates a feeling of normalcy for the Living and Dying, as it is often hard to find a sense of normalcy in a relationship after a terminal diagnosis. For Nik, most of the FC that he engaged in was everyday talk. His grandmother had lived with him for most of his life, so his everyday talk mainly took place at the dinner table with him, Effie, his brother, Christopher, and the rest of their family.

"A lot of our time was us, you know, at the dinner table. We always had family dinners like every night, so we would see each other every day, like a lot, I mean we lived in the same house for

12 or 13 years, I wanna say. I lived with her, and we would see each other every day.” (Nik, 23)

Also, during errands that Nik would run with Effie, they would get to have quality time to talk about their lives with one another. During this time, opportunities for FC occurred, and Nik utilized them through everyday talk. Nik stated:

*“But, you know, as much as like, apart from good morning, how are you, and just like general chats and stuff like that, we would just do our own stuff as anybody living in the same house with a family member would do. And so these times in which we would do like errands with each other were the times that we like got to have
“Nik and Ya Ya [Effie] one-on-one talks.” (Nik, 23)*

Christopher, Nik’s older brother, also engaged in everyday talk with Effie. Effie would greet him, and Christopher would make the decision to turn her greetings into everyday talk. Christopher stated:

“She had a lot of like little things she would say, and she would often say hello and stuff, but it was my decision to make them into conversations. Uhm, you know, I think grandparents are always very, or at least in my experience, they don’t want to like get all up in your business necessarily. Maybe not everyone’s grandparents are like that, but Ya Ya [Effie] basically would say hello, but then it was my call with whether I wanted to talk about my day and that kind of stuff.” (Christopher, 26)

Although Christopher turned his everyday talk into longer conversations, shorter conversations with everyday talk can occur. When a person begins declining, conversations often become briefer. Katie's everyday talk with Sophie* demonstrates this when Sophie* would ask her about job hunting every time she saw her. Sophie* had suffered from a stroke, and so conversations were a little tougher in their relationship, so they had to be kept to a minimum.

“She knew I was looking for a job at the time, and I had just started graduate school, and I was trying to find a way to pay for graduate school and she kept on asking like you know, “How’s the job search going?” And that kinda was the extent of it, yeah it was just, it wasn’t really conversations sometimes, it was just her rambling.” (Katie, 23)

Even during the very last conversation the Living has with the Dying, everyday talk can be utilized. During Jamielee's last talk with her grandmother, she engaged in everyday talk for the duration of it. Jamielee knew it was Sue and hers last phone call, and decided to keep their conversation to what they would normally talk about.

“And so, we just talked about her day was and how she was feeling. She wasn’t feeling great, but she had the energy to talk and sometimes she didn’t but then she got tired, she got too tired to talk after a little bit and I think we talked for like 20 minutes. And that was it.” (Jamielee, 21)

Everyday talk is not just verbal communication, it can also be nonverbal. Actions can be habitual and considered normal in a relationship. Kathleen grew up next to her

best friend and her mother, Sara, and began habitually walking into their house without knocking. This was understood as an okay action to take, as both Kathleen and Sara felt that they were close enough to let this happen. Once Sara was diagnosed with liver cancer, Kathleen continued to walk into their house without knocking, and therefore continued on using normal, everyday behaviors between her and Sara. Kathleen felt like Sara was her second mother, and the feeling was reciprocated in their relationship.

“I mean, I just walked into their house. It was just one of those. I went to pick up Megan, I got out of the car, I walked in. I could just walk in. I’ve lived next to them for mmm I moved in when I was three, so I’ve known them for like 17 or 18 years. And so I just walked in and she was like my second mom. I was just like, “Hi Mrs. Sara!” and she was like, “Oh, Kathleen!” and I was like, “Hi Mrs. Sara!” So. It was probably like just a normal conversation that I walked in to, like I would have with my mom. I would just walk in.” (Kathleen, 21)

Seven out of nine millennial participants engaged in everyday talk at the EOL. Everyday talk is utilized to create a feeling of normalcy in a relationship by keeping daily conversations as they were before terminal diagnosis (Keeley, et al, 2014). Discerning this emerging theme in FC engaged by millennials reveals a need to keep conversations to things that make both the Living and the Dying comfortable and familiar in their relationship. This is important insight into how millennials deal with the change caused by a terminal diagnosis.

HELPING TASKS

The fourth most common theme that emerged during millennial participants FC was helping tasks, and occurred in five out of the nine interviews. These tasks were all nonverbal, as aiding a person with a task doesn't come from words, but actions. Often, at the end of life, the dying becomes too weak to perform daily activities and may require assistance from a healthy individual to get tasks done. These tasks can be mundane tasks like brushing teeth, making food, cleaning the house etc., and they can also be larger tasks like aiding a person with physical therapy. Grace* would often help her father with physical therapy once he lost the ability to move the right side of his body due to a cancerous brain tumor affecting his mobility. It became something that they did together, and Grace* was happy to make Samuel* get out of bed and move his body.

“When my dad got sick, within the first month, he went from a can, to a walker to a wheelchair. He lost the ability to move the right side of his body. And his like right side of his face and everything. Also he lost a lot of his memory, his ability to talk, to write, all of those things were all gone. So a lot of what we did was forcing him to get up. He just wanted to sit on the couch and I refused to let him. That was my big thing. I would stretch out his arm, I would stretch out his leg, I would do all this physical therapy stuff with him. And then, I'd be like, “okay we're going to go walk a block. And he's be like, “No, I don't wanna move.” And I'm like, “I wasn't asking.” So it became a thing. I kinda forced him to move and that was, yeah that was kinda our biggest thing.” (Grace, 19)*

Like Grace*, aiding his grandmother in a daily task became a recurring thing that Christopher did. Christopher would often push his grandmother in her wheelchair and take her to doctors' appointments and grocery shopping. Christopher enjoyed being apart of Effie's life in that way, and was able to bond with her during their time together at the EOL. It was the most meaningful to him when he was able to aid Effie in simple actions for him, but daunting ones for Effie, who was disabled and wheelchair-bound.

"I liked pushing her around in the wheelchair... I really like doing that kind of stuff for people. It just makes me feel like I can really step up and be apart of someone's life in that way. So I liked pushing the wheelchair and taking her to hair appointments and doctor's appointments and pushing her around the hospital in a wheelchair and stuff like that. She always made it really fun and was always very grateful that I took her places. Which was really cool. And I think that a nonverbal relationship where it's just the act of moving someone around and there's not necessarily speech involved, it's just you are their wheels and it's like exact type of thing that they would have to pay someone else to do, but you do it just because. I feel like that's a cool relationship."

(Christopher, 26)

Christopher also stated:

"There's kind of like a beauty and a poignancy in physical transportation. Like where, especially for someone who isn't very mobile, it's something that takes so little effort from you, but

means so much to them. And that kind of like weird power dynamic makes everything like really exuberant, I don't know, maybe that's not the word, but it makes everything like glow about it. Like you can be like an amazing wonderful person to this person just by pushing something, just by doing something so easy to you, I think it's similar to having any one or anything that relies on you, like it's the kind of relationship that you might also have with a pet, where it's like this person or this entity relies on me for even food or water and it's like just by giving water or giving food or giving transportation or giving like a hand into the car I can like make this person's day. And so, it feels like simple actions become transformed into things that are really meaningful."

(Christopher, 26)

Nik, Christopher's younger brother, would also often aid Effie by driving her to and from errands that she needed to complete. When talking about the FC he engaged in, Nik recalled that his mother or grandmother would often ask for his aid when Effie needed to make an appointment or go to the grocery store, and he would always gladly comply with their requests to do so. He enjoyed the quality time they were able to spend together during those moments, and was glad to help.

"I don't know, again I guess like, it was, you know, us doing favors for each other. I guess it was technically 'cause I think she would probably be too shy, no, she wasn't too shy to ask, I guess it was usually my mom telling me or letting me know or asking me if I

would drive her and then like she'd be like, from these dates to these dates, it wasn't like a wake up every day and have my mom ask me to drive her to this thing. I think Ya Ya [Effie] would like sometimes be like "hey if I can't find anyone else I might have to ask of your chauffeuring." Then I was like yeah that's totally fine."
(Nik, 23)

Nico would also often aid his grandmother, Otelia, with mobility, automatically aiding her with walking and matching her pace, which was slower than his, to accommodate for his height.

"When we would get out of the car or walk into the restaurant or anywhere, I'd always have her hold my arm and just walk with her. I was almost a foot and a half taller than her, so my stride is a lot longer than hers, so I would definitely slow my pace down just to have her keep up." (Nico, 23)

Katie would also help her grandmother by pushing her wheelchair out to view the Christmas tree in her nursing home, which was a favorite activity of Sophie's* during the holidays.

"Yeah, uhm, I mean I couldn't lift her into the wheelchair but, so we would have someone from the nursing home lift her into the wheelchair, and then we would wheel her out to the Christmas tree." (Katie, 23)

Five out of the ten millennial participants participated in helping tasks to aid the dying at the EOL. This emerging theme reveals an eagerness from millennials to help and

aid the dying during their FC. Knowing this about millennials gives us a better understanding of how millennials like to engage the dying during FC at the EOL, and says a lot for their awareness of their youth and their capabilities of aiding an old human that has lost most of their mobility.

DISCUSSION

The purpose of this study was to discern common themes in the verbal and nonverbal FC that millennials engage in with the dying at the EOL. The researcher sought to understand millennial's FC to spark interest in learning more about how they engage in FC. This research will also extend the existing literature on final conversations, as done by Keeley and her colleagues (Keeley, 2004, Keeley, 2007, Keeley & Yingling, 2007, Generous & Keeley, 2014, Keeley, Generous, & Baldwin, 2014, Manusov & Keeley, 2015, Keeley, 2016).

Understanding how a millennial engages in FC at the EOL is a big determiner for how we, as a society, currently feel about and discuss death. The interview questions in this study served as a trigger to gain insight on a millennial's behavior toward a person who was dying, and five key themes emerged in the data findings: love, avoidance, messages about the future/past, everyday talk, and helping tasks. This reveals what is important for a millennial to discuss at the EOL and answers the research question: What are the verbal and nonverbal messages millennials report were exchanged during final conversations with the dying? Since the grieving process now begins at the time of diagnosis, FC can be extended to several months and even years (Keeley, 2007). The data findings will help guide future millennials, as well as generations seeking to understand them, through their FC and allow them to decide for themselves what they need as an individual when engaging in FC.

LIMITATIONS

Despite the first-hand insight into how millennials engage in FC, this study accrued some limitations. Due to time constraints that were created because of a delay in IRB approval, the researcher was forced to interview a sample that was smaller than originally hoped for. In addition, the majority of participants were observed to be white/Caucasian and the rest were of other ethnicities. If given more time to create a diverse sample, this study may have benefited, as minorities' experiences with FC and a dying loved one could potentially have differences from the majority.

FUTURE DIRECTIONS

This study revealed a greater need to provide examples of FC to millennials whom have not yet experienced the permanence of a goodbye before death and a need to navigate through those types of conversations for the first time. Millennials will be the population that will bear the greatest burden of caring for their aging family members that are a part of the baby boom generation, thus emphasizing the importance of increasing their understanding of the importance of FC with their family members. There is a great deal to be learned about the communication at the EOL from the millennials perspective.

CONCLUSION

This research revealed a greater need to extend existing research on millennials and further learn about the millennial population's FC at the EOL. Extensive research has already been done on FC, and this investigation adds to the existing literature by providing insight on how the millennial generation engages in FC with the dying. The data findings also reveal how a millennial engages with the dying, thereby highlighting how they engage with aging family members and how they deal with death. Avoiding the topic of death during FC was common among millennials, and reveals a need to lessen the negative significance placed on death in our culture and allow for millennials to become comfortable with the prospect of death, and the finality that comes with it.

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In future correspondence please refer to 2017921

October 26, 2017

Natalie McRae
Texas State University
601 University Dr.
San Marcos, TX 78666

Dear Ms. McRae:

Your application 2017921 titled, "Final Conversations from the Millennial Generation," was reviewed by the Texas State University IRB and approved. It has been determined there are: (1) research procedures consistent with a sound research design and they do not expose the subjects to unnecessary risk. (2) benefits to subjects are considered along with the importance of the topic and that outcomes are reasonable; (3) selection of subjects is equitable; and (4) the purposes of the research and the research setting is amenable to subjects' welfare and producing desired outcomes; that indications of coercion or prejudice are absent, and that participation is clearly voluntary.

1. In addition, the IRB found that you need to orient participants as follows: (1) informed consent is required; (2) Provision is made for collecting, using and storing data in a manner that protects the safety and privacy of the subjects and the confidentiality of the data; (3) Appropriate safeguards are included to protect the rights and welfare of the subjects.

This project is therefore approved at the Expedited Review Level until February 28, 2018

2. Please note that the institution is not responsible for any actions regarding this protocol before approval. If you expand the project at a later date to use other instruments, please re-apply. Copies of your request for human subjects review, your application, and this approval, are maintained in the Office of Research Integrity and Compliance.

Report any changes to this approved protocol to this office. A Continuing Review protocol will be sent to you in the future to determine the status of the project. Notify the IRB of any unanticipated events, serious adverse events, and breach of confidentiality within 3 days.

Sincerely,

Monica Gonzales
IRB Regulatory Manager
Office of Research Integrity and Compliance
Texas State University

CC: Dr. Maureen Keeley

OFFICE OF THE ASSOCIATE VICE PRESIDENT FOR RESEARCH

601 University Drive | JCK #489 | San Marcos, Texas 78666-4616

Phone: 512.245.2314 | fax: 512.245.3847 | WWW.TXSTATE.EDU

This letter is an electronic communication from Texas State University-San Marcos, a member of The Texas State University System.



The rising STAR of Texas

IRB Application

Texas State University Institutional Review Board

Section I: Filling Out and Saving the Form

Save this application on your desktop. Upon completion, upload it along with all supplemental documents to the applicable project listed on your on-line IRB Home Page.

Section II: General Information

1. Title of Study

Insert the project name below. It should be identical to the title of any related internal or external grant proposal.

Final Conversations from the Millennial Generation

2. Investigator (Primary Research)

First Name	Last Name	Title (i.e. grad student, student, etc.)
Natalie	McRae	Students
Degree Program/Department	Texas State Email Address	Phone Number
Communication Studies	nlm50@txstate.edu	5129173608

If you are a student, is this application for your thesis or dissertation research?

☒ Yes

☐ No

3. Co-Investigator or Texas State University Sponsoring Faculty (if applicable)

First Name	Last Name	Title (i.e. grad student, student, etc.)
Maureen	Keeley	PhD
Degree Program/Department	Texas State Email Address	Phone Number
Communication Studies	maureen.keeley@txstate.edu	5122453133

4. Project Dates

Anticipated Start Date: August 28, 2017

Anticipated End Date: December 31, 2017

Section III: Risk Review

Please click the box indicating your answer to each of the following questions:

1. Will your research study involve any vulnerable populations such as children, prisoners, pregnant women, mentally disabled persons, cognitively impaired elderly , or minority ethnic groups?
☐ Yes
☒ No
2. Could public disclosure of any identifiable data you collect place the participants at risk of criminal or civil liability or be damaging to the participants' financial standing, employability or reputation?
☐ Yes
☒ No
3. Will your study involve data collection procedures other than surveys, educational tests, interviews, or observation of public behavior?
☐ Yes
☒ No
4. Will your study involve the collection of sensitive data such as: illegal drug use, alcohol abuse, victims of violence, health history, prior diagnosis of mental disorders, sexual activity, criminal activity, or personal academic history?
☐ Yes
☒ No
5. Will your study involve audio or video-recording research participants?
☒ Yes
☐ No
6. Will your study involve obtaining individually identifiable information from health care providers, clearinghouses, or plans?
☐ Yes
☒ No
7. Will you be collecting anonymous data (results cannot be linked to individual participants)?
☒ Yes
☐ No
8. Will you be using data that was previously approved by the Texas State IRB?
☐ Yes
☒ No

If yes, please provide the Texas State IRB approval number:

9. Will you be using data that was previously approved by a non-Texas State IRB at an another institution, organization, center?

☐ Yes
☒ No

If yes, please provide the name of the institution/organization and upload the applicable original IRB approval that authorized the data collection:

Were you provided and instructed to sign and complete a Data Use Agreement (DUA)?

☐ Yes
☒ No

If yes, please provide a copy of the agreement. Please note that the AVPR is the only University official authorized to sign this legally binding document.

10. Does this project SOLELY involve analysis of publicly available existing database?

☐ Yes
☒ No

If yes, please provide the complete URLs for all databases that are relevant to this application:

**If you answered yes to questions 8, 9, or 10, please submit the appropriate documents and only complete the Purpose of Study (1), Previous Research (2), and Publication of Results (11) in Section IV of this application.*

Section IV: Research Protocol Information

1. Purpose of Study

Provide a brief summary of the proposed research. Include the hypothesis and research design.

The purpose of this research is to collect and examine recounts of final conversations from the point of view of millennials who continue to live after their loved one has passed. Final conversations are any conversations that happen between a millennial and a loved one after their terminal diagnosis (i.e., both parties knew that he/she was dying). The research question is, "What kinds of final conversations do millennials have?" Interviews will be audio-recorded, and nine questions will be asked of the participants about their experiences with final conversations. Common themes will be discerned from these conversations, and the research will be used in my undergraduate thesis.

2. Previous Research

Briefly summarize previous research leading to the formulation of this study, including any past or current research conducted by the Investigator that leads directly to the formulation of this study.

I have read the book "Final Conversations" by Dr. Maureen Keeley and asked to do research with her on millennials, a demographic that she has not previously focused on. Dr. Keeley has been conducting research on Final Conversations since 2000. Regarding her publications on Final Conversations, she has published a co-authored book, was a special guest editor for Behavioral Sciences (an on-line, open access journal) titled "Family Communication at the End of Life" and has authored or co-authored 35 articles, chapters, and/or encyclopedia entries.

3. Recruitment of Participants

Describe the source(s) of subjects and the selection criteria. Include the gender, racial/ethnic composition, age range, occupation, etc. Specifically describe how will you recruit and contact potential subjects. Also, include the anticipated number of research participants. All recruitment materials such as flyers, e-mails, verbal scripts, advertisement, etc. are required to be submitted and approved by the IRB.

There will be 10 total participants. The main source of participants will be millennial students that have/ do attend (ed) Texas State University. One other source will be acquaintances. All genders will be welcome to participate, as well as all races and ethnicities. The only requirements in selecting participants are an age range from 18 years to 37 years and Final Conversation talk with a terminal loved one. All occupations are welcome. Recruitment over email will occur as well as word of mouth. Official recruitment will take place once I send out my email script and the attached consent form. From there, participants will be asked to contact me over email or by phone (both my email and phone number will be provided in the email script) in order to set up an official interview date and time. The interviews will take place in Dr. Keeley's private office in Centennial RM 301. I will receive the emails of participants either over text or in person, either from the participant themselves or Dr. Keeley. Participants recruited by Dr. Keeley will have been informed of the study in her communications classes by word of mouth.

4. Vulnerable Populations

Please identify any vulnerable populations that will be recruited to participate in this study:

- | | |
|---|---|
| <input type="checkbox"/> Children | <input type="checkbox"/> Pregnant Women |
| <input type="checkbox"/> Prisoners | <input type="checkbox"/> Mentally Impaired |
| <input type="checkbox"/> Cognitively Impaired Elderly | <input type="checkbox"/> Ethnic Minorities, Non-English Speaking Individuals |
| <input type="checkbox"/> Other: Please list: <input type="text"/> | <input checked="" type="checkbox"/> N/A, this study will not use vulnerable populations as research participants. |

If applicable, describe any special precautions that will be taken for the inclusion for identified vulnerable populations. I.e., use of informed assent and parental consent for minors or consent documents in an alternative language for individuals who do not speak English.

5. Informed Consent

Describe the consent process and upload all consent documents. If you are requesting a waiver of signed informed consent, please state the rationale and how consent will be alternatively obtained (verbal, "clicking" an on-line button or link, participation will imply consent, etc.)

An email will be sent out to the participant's emails that includes the email script and the consent form I provided. A consent form will be provided before any information is asked for from the participant and before they contact me to sign up for an interview. Before the interview, the participant will be asked to re-read sign the consent form and verify whether or not they want a pseudonym to be used in my undergraduate thesis. A paper copy of the consent form will be provided before the interview begins to re-read so they are able to ask questions before the interviews begin.

6. Procedures

Provide a step-by-step description of each procedure, including the frequency, duration, and location of each procedure. Also, for data collection sites other than Texas State that involves the authorization and coordination with an outside agency, please upload a signed and dated letter on the cooperating institution's letterhead granting approval for the data collection.

From the email script and the consent form that I email to participants, they will reply to schedule an interview time. Before the interviews begin, a paper copy of the consent form will be provided for the interviewee to sign and choose whether they want a pseudonym used in my undergraduate thesis. Each interview will last 30-45 minutes. It will be audio-recorded, and then transcribed after the interview's completion. The interviews will take place in Centennial Hall at Texas State University, in Dr. Maureen Keeley's private office, RM 310. After the completion of the thesis, the participants will have the option to receive a summary of the findings, to which the findings will be sent to the emails they provided. My email is provided in the consent form to contact if they choose to receive the summary.

7. Confidentiality

Describe the procedures that will be used to maintain the confidentiality of all personally identifiable data. (Please note: All data must be securely kept for a minimum of three years on campus. The location of the secured data should be listed below.)

No last names of participants will be shared with outside parties that are not Dr. Keeley and myself. First names may be used in my undergraduate thesis, but only if the participant marks that they are okay with that in the consent form. If the participant wants a pseudonym to be used, then they may request for one under the Extent of Confidentiality section in the consent form, and as a result no last names or first names will be shared with outside parties other than Dr. Keeley and myself. The audio-recordings of the interviews will not be shared with outside parties that are not Dr. Keeley and myself. No one will be present during the interview other than the participant, Dr. Keeley, and myself. All data will be stored in a password protected laptop with myself and a password protected computer with Dr. Keeley. The emails of participants will be stored in a file that is separate from the audio-recorded and transcribed interviews. Identifiable data will be destroyed after 5 years.

8. Risks

Describe any foreseeable or anticipated risks that may be presented to the participants as a result of taking part in the study. Please describe all of the precautions that will be implemented to minimize such risks.

There may be some minimal risk in answering questions about final conversations that could trigger an emotional response associated with the feelings of loss and grief. Participants will be made aware that they can leave the survey at any time if these emotions become too intense for them. In addition, calling a grief counselor at hospice will be suggested as well as information on how to contact the Texas State Counseling Centre will be provided in the consent form.

9. Benefits

Describe the anticipated benefits to subjects, and the importance of the knowledge to your field that may reasonably be expected to result.

The benefits to participants may include increased awareness of the gifts the participant's final conversation brought them, advancement of the grieving process, and relief that comes with emotional expression. Facing death often "frees" people in the types of conversations that they are willing to engage in, thus leading to more openness in relationships. The goal of the investigators is to identify the possible "gifts" that can be found in the conversations with our loved ones and to publish the findings as inspiration for those individuals who, in the future, will be faced with the death of a loved one. This study hopes to highlight the role and impact of "final conversation" on healing for the bereaved.

10. Compensation

Describe any compensation subjects will receive for participating in the study. Include a description of the compensation, timing for payment, and conditions for receipt of such compensation. Please note: If extra course credit is offered as an incentive for participation, the instructor must provide an alternative form of extra credit to students who do not want to participate in the research.

No compensation will be provided, the interviews will be volunteer-based.

11. Publication of Results

Please identify all methods in which you may publicly disseminate the results of your study.

- | | |
|--|--|
| <input checked="" type="checkbox"/> Academic Journal | <input checked="" type="checkbox"/> Thesis or Dissertation |
| <input checked="" type="checkbox"/> Academic Conference Presentation | <input type="checkbox"/> Texas State University Scholarly Works Repository |
| <input checked="" type="checkbox"/> Academic Conference Poster | <input type="checkbox"/> Other: Please list <input type="text"/> |
| <input type="checkbox"/> Book or Textbook Chapter | |

Section V: Investigator Certification

- ☒ By checking this box, I am certifying that the information in this application is complete and accurate. I agree that this study will be conducted in accordance with Texas State IRB Guidelines. I will request IRB approval before making any modification to the research procedures or forms. I understand that neither recruitment nor data collection will be initiated until final IRB approval is received. I will notify the IRB any unexpected or otherwise significant adverse events and general problems within one week of the incident. I understand that if these conditions are not met, this research could be suspended and/or not recognized by Texas State University.

This application and all supplementary documents must be submitted together to be processed for review. The IRB will contact you if additional information or revisions are needed for approval. All revisions must be submitted within 30 days of the request. After that time all the application will be discontinued. If your application is discontinued you will be required to resubmit another application.

Contact The Office of Research Integrity and Compliance at (512) 245-2334 or avpr-irb@txstate.edu for any questions concerning the approval status of your application.

**Email Script
for
Final Conversations With Millennials**

To: [Use this line for individual addresses or your own address if BCC line is used]
From: [Principal Investigator]
BCC: [Use this line when sending the same email message to multiple addresses]
Subject: Research Participation Invitation: [Research project title, topic or key words]

This email message is an approved request for participation in research that has been approved or declared exempt by the Texas State Institutional Review Board (IRB).

Dear _____,

My name is Natalie McRae, and I am a Communication Studies student at Texas State University. I am currently conducting research for my thesis entitled "Final Conversations With Millennials" under the supervision of Dr. Maureen Keeley. If you have had an experience with a loved one, in which you both knew he/she was dying, and are between the ages of 18 and 37, you are invited to participate in this study. Attached is the consent form that will be provided that includes more details of the study.

Thank you for your time,

Natalie McRae
Communication Studies
Honors College
PACE Peer Mentor
nlm50@txstate.edu

This project 2017921 was approved by the Texas State IRB on October 26, 2017. Pertinent questions or concerns about the research, research participants' rights, and/or research-related injuries to participants should be directed to the IRB chair, Dr. Denise Gobert 512-245-8351 – (dgobert@txstate.edu) or to Monica Gonzales, IRB Regulatory Manager 512-245-2334 - <mailto:meg201@txstate.edu>).



INFORMED CONSENT

Study Title: Final Conversations with the Millennial Generation

Principal Investigator: Natalie McRae
Email: nlm50@txstate.edu
Phone: 512.917.3608

Co-Investigator/Faculty Advisor: Dr. Maureen Keeley
Email: maureen.keeley@txstate.edu
Phone: 512.245.3133

This consent form will give you the information you will need to understand why this research study is being done and why you are being invited to participate. It will also describe what you will need to do to participate as well as any known risks, inconveniences or discomforts that you may have while participating. We encourage you to ask questions at any time. If you decide to participate, you will be asked to sign this form and it will be a record of your agreement to participate. You will be given a copy of this form to keep.

PURPOSE AND BACKGROUND

This research study aims to collect and examine recounts of Final Conversations (FC) from the point of view of millennials whom continue to live after a loved one (e.g. parent, sibling, spouse, friend) has passed. The information gathered will be used to discern common themes discussed during the FC talk of millennials. You are being asked to participate because you have been identified as a millennial between the ages of 18 and 37 who has had a final conversation(s).

PROCEDURES

You are being asked to complete a 30-45 minute interview regarding your Final Conversations with your terminally diagnosed loved one. We will set up a time for you to meet one of the investigators at Dr. Maureen Keeley's Office located in Centennial, RM 301.

Any information I give during my participation in this study will be used for research purposes only. The investigator(s) anticipates the completion of her undergraduate honors thesis and perhaps a brief article co-authored by the advising thesis director (Dr. Maureen Keeley) presented at a conference or published in an academic journal.

RISKS/DISCOMFORTS

There may be some minimal risk involved in so much as answering the questions about your final conversations may trigger some emotions associated with your loss and grief. If you do feel that any of the items trigger emotions too intense for you to handle, please contact the grief counselor at hospice or a grief counselor at a local counseling center in your area. In addition, you may exit the survey at any time.

In the event that some of the survey or interview questions make you uncomfortable or upset, you are always free to decline to answer or to stop your participation at any time. Should you feel discomfort after participating and you are a Texas State University student, you may contact the University Health Services for counseling services at 512.245.2208. They are located on the 5th floor of the LBJ Student Centre.

BENEFITS/ALTERNATIVES

The benefits to participants may include increased awareness of the gifts their final conversation brought them, advancement of the grieving process, and relief that comes with emotional expression. Facing death often “frees” people in the types of conversations that they are willing to engage in, thus leading to more openness in relationships. The goal of the investigators is to identify the possible “gifts” that can be found in the conversations with our loved ones and to publish the findings as inspiration for those individuals who, in the future, will be faced with the death of a loved one. This study hopes to highlight the role and impact of “final conversation” on healing for the bereaved. You may have a summary of the findings of the study once it has been completed by contacting Natalie McRae at nlm50@txstate.edu.

EXTENT OF CONFIDENTIALITY

Reasonable efforts will be made to keep the personal information in your research record private and confidential. Any identifiable information obtained in connection with this study will remain confidential and will be disclosed only with your permission or as required by law. The members of the research team and the Texas State University Office of Research Compliance (ORC) may access the data. The ORC monitors research studies to protect the rights and welfare of research participants.

Data will be kept for five years after the study is completed and then destroyed.

PARTICIPATION IS VOLUNTARY

You do not have to be in this study if you do not want to. You may also refuse to answer any questions you do not want to answer. If you volunteer to be in this study, you may withdraw from it at any time without consequences of any kind or loss of benefits to which you are otherwise entitled.

COMPENSATION

You will not be paid for your participation in this study.

QUESTIONS

If you have any questions or concerns about your participation in this study, you may contact the Principal Investigator, Natalie McRae: nlm50@txstate.edu.

ABOUT FACULTY THESIS SUPERVISOR

Dr. Maureen Keeley, PhD., Professor in the Department of Communication Studies. Dr. Keeley has been conducting research on Final Conversations since 2000.

This project was approved by the Texas State IRB on October 26, 2017. Pertinent questions or concerns about the research, research participants' rights, and/or research-related injuries to participants should be directed to the IRB Chair, Dr. Denise Gobert 512-245-8351 – (dgobert@txstate.edu) or to Monica Gonzales, IRB Regulatory Manager 512-245-2334 - (meg201@txstate.edu).

DOCUMENTATION OF CONSENT

I have read this form and decided that I will participate in the project described above. Its general purposes, the particulars of involvement, and possible risks have been explained to my satisfaction. I understand I can withdraw at any time.

Printed Name of Study Participant

Signature of Study Participant

Date

Signature of Person Obtaining Consent

Date

I request that researcher(s) use my real name (first name only) in any/all work and publication(s):

_____.

I request that the researcher(s) use the name of my loved one (first name only) with whom I had a final conversation and in any/all work and publication: _____.

I confirm that I would like the researcher(s) to use a pseudonym for my name and that of the person that I had this final conversation: _____.

