

## ABSTRACT

### DEATH ACCEPTANCE AND INTIMATE RELATIONSHIPS

by Hideaki Imai

Although researchers have investigated death attitudes since the 1960s, only a few have examined death acceptance as a research topic. Furthermore, most of these studies focused on quantitative assessments without finding consistent results. In this study, I conducted a qualitative investigation on the role of intimate relationships in accepting death. I interviewed four older adult participants about their death attitudes and intimate relationships in semi-structured interviews. From the results, I found that the male participants needed to deepen their relationships before accepting death, whereas the female participants already had intimate relationships and were able to accept death immediately as they became aware of their mortality.

DEATH ACCEPTANCE AND INTIMATE RELATIONSHIPS

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## Introduction

In this research project, I present a qualitative exploration of older adults' acceptance of death and the role of intimate relationships in the process of accepting death. By “death acceptance,” I mean the way in which the participant acknowledges his or her process of dying without being threatened by it. For defining intimate relationships, I use the concept of ROLE relationships within the theoretical framework of Experiential Personal Construct Psychology – relationships in which one person understands the ways in which the other construes the world (Leitner, 1985; Leitner & Faidley, 1995).

In the initial conception of this project, I planned to work with terminally ill patients in order to start a conversation about death among the living. However, I have come to find out that I do not need to ask those who are actively dying to investigate death; rather, I can ask older adults who are aware and accepting of death to facilitate a discourse on accepting death and our intimate relationships. Though I initially sought to recruit participants from a hospice setting, I eventually worked with those who are either in a nursing home, or older adult community members.

Before discussing the details of the study, I first will introduce my motivation behind pursuing this project. After introducing my personal motivation, I will discuss how my research question can be important for all of us who are living. Once I establish the personal and public importance, I will provide a review on the past psychological literature that investigated death acceptance. Following the literature review, I will discuss the theoretical framework in which this project operates. Specifically, I will present the way the concept of ROLE relationships fits with the concept of death-acceptance. After the theoretical discussion, I will explain how I executed this project in the Method section, introduce what I found in the Results section, and talk about implications in the Discussion sections.

### My Story

As I planned to ask my participants to share their stories for this project, it is only fair that I disclose my story. Moreover, given that this is a qualitative study wherein the researcher's interpretation of the data is explicit, I will reveal some aspects of my background that are relevant to this project. Hence, I will introduce my personal experiences with death and intimate relationships.

My fascination with death started when I learned about the philosophy of death in a class on existentialism. Following my newfound academic passion, I decided to write my senior project on people's attitudes towards death. The project was a psychological study on whether people's death attitudes affect their psychological well being. Illustrating my newfound interest, I even dressed up as the grim reaper for the Halloween of 2008.

Two weeks after Halloween, I received an email from my father in which he informed me that my grandfather had terminal cancer. During winter break, I flew to Japan to see my grandfather on his deathbed. As I saw him so thin and immobile, for the first time I realized that he was actually dying. As it was my last chance, I asked him questions about the entirety of his life – his childhood, his family, and his reasons for pursuing his profession – neurosurgery. Our last meetings were also opportunities in which I could tell him about my future aspirations – how I wished to be a therapist, a professor, and a psychologist. Essentially, we both sought professions in which we “help” people. Hence, it was meaningful that my grandfather could talk to me about the nature of “helping” from his experiences. Interestingly, it was the first time I felt as though I got to *know* my grandfather; I learned then the irony of realizing how much another individual means to me only when the relationship comes close to an end.

As my winter break approached its end, I had to finish my hospital visits. I remember being nervous about saying goodbye to him. I was nervous, because I did not know what it was going to be like to see a person, a family member, for literally the very last time in my life. What strongly resonates is the image of him staring back at me, as I looked into his eyes – it gave me a convincing impression that he too knew it was going to be his last time seeing me in his life.

After returning to the United States, I received an international call from Japan on my birthday, February 16<sup>th</sup>, right in the middle of my data collection for my undergraduate death project. I heard my father on the other end, weeping for the first time since my childhood. With audible effort, he told me that my grandfather had just passed away. After I hung up the phone, I remained composed as I was in front of students who were filling out my questionnaires. After the data collection, I had dinner with my friends and we celebrated my birthday. After dinner, I finally started crying, and I could not get my tears to stop.

As my birthday is also my grandfather's death anniversary, I consider the topic of death profoundly personal, and one that I feel destined to explore. What was it like to recount his career, relationships, and life experiences to his grandson who was so interested in knowing everything about him, so desperate to keep the connection that he had in the very last minute? Such questions may not find answers, but they inspire a curiosity that I find worth pursuing. In retrospect, I remember my grandfather's refusing the doctor's offers for various medications and procedures to prolong his life. It seemed like he was very ready for his death.

Hence, frankly, this project is a personal one. Without making my personal motives explicit, I presented my thesis idea to explore death acceptance and intimate relationship at a group meeting. When I asked for feedback for this project, I received a question: "Why should anyone care about this project?" I knew that the person who asked the question did not mean to be caustic, but was just asking to facilitate a discussion. However, never having asked the question in such a way, I found myself in a panic, unable to respond in a coherent manner. Perhaps this study was so personal that I never gave a thought about how it could be valuable to other people.

Upon further consideration, however, I realize that the subject matter of accepting death is important for all of us. Religious debate about afterlife aside, death is a universal phenomenon. Every one of us dies. As Heidegger (1962) states, the fact that our life will come to an end raises the question of how we should live our lives in a fulfilling manner. However, as Becker (1972) states, most of us are hesitant to bring up the topic of death. When death is an often-avoided topic, we might be overlooking lessons about life that we can learn only through confronting death. Hence, listening to those who are already aware and accepting of their mortality will start a conversation about death.

### **Past Theorists and Researchers**

Many theorists and researchers on the subject of death assert the profound influence of confronting death for the way one lives life (e.g., Heidegger, 1962). Such a notion was the basis for Heidegger's argument for authenticity. When death is seen as avoidable, we would live as though there is unlimited time to partake in whatever activity that we like. However, any activity we wish to participate in would eventually lose its value, if there were an infinite number of times we can participate in it. Hence, he concluded that the limit of our mortality is required for our lives to be meaningful; instead of being in denial of mortality, we should be accepting and joyful. He suggested that the *authentic* mode of living would be to live with the awareness of death.

Ernest Becker (1972) is another thinker known for his contribution to the study of death attitudes. With his book, *The Denial of Death*, Becker spawned a movement investigating human being's death-denying tendencies, known as Terror Management Theory (Rosenblatt, Greenberg, Solomon, Pyszczynski, & Lyon, 1989). In his book, Becker made two observations about human nature: that we are 1) self-preserving and 2) self-conscious. While we want to preserve ourselves, our self-consciousness brings about our awareness of mortality. According to Becker, the contradiction between our self-preserving nature and our mortality awareness is a great source of our fear. Given that death is the source of ultimate fear for us, we try our utmost not to face our own mortality by clinging to our cultural defenses. He states that we partake in cultural activities, such as constructing a pyramid or giving birth to a child, in part because these activities result in the construction of entities that

outlive our ephemeral life. Hence, they serve the function of “denying” death. Becker’s conclusion implies that death and life are inseparable concepts, given his statement that we partake in many activities to manage our fear towards death.

Elizabeth Kubler-Ross’s (1969) motivation was similar to mine when she interviewed terminally ill patients for her project in *On Death and Dying*. My project focused on the role of intimate relationships in death acceptance, whereas hers sought to explain how the terminally ill go through the stages of dying. Although different in focus, both Kubler-Ross and I share the assumption that the topic of death is relevant to all of us who are living. In doing so, Kubler-Ross encouraged us to approach the dying rather than to retreat from them. In addition, Feifel (1990) seemed to share the same argument – he understood that our death attitudes affect how we live. He made it explicit that, “How we anticipate death future events – and death – governs our 'now' in substantive fashion and provides an important organizing principle to life” (p. 541). Imara (1975) exemplified Feifel’s claim through a case study, in which a dying interviewee stated, “I have lived more in the past three months than I have during my whole life. I wish I knew forty years ago what I know now about living” (p.151). Her statement may imply that she would have benefited from knowing what it was like to die, even in her youth. Hence, it seems that death is, in fact, a relevant and desirable topic to explore for those of us to whom death seems as though a foreign and distant event.

Recent researchers also encourage conversations about death. Wyatt (2009), for example compiled “lessons” from her patients she saw under hospice care. She found themes such as “dwelling in the present moment” as well as “letting go of expectations.” As a doctor who saw dying patients for eight years, the stories from the dying deeply affected her. She hoped that her compilation of lessons would inspire others throughout the world. Block and Billings (2005) also reported that Harvard medical students are offered a course called “Living with a Life-threatening Illness.” In the course, students interact with terminally ill patients as teachers so that they can learn how to listen to the dying.

For health care professionals who wish to take care of those who are dying, accepting death seems to have a profound effect on how they treat their clients. For example, Tucker (2009) claimed that doctors and medical students who show death denying tendencies tend to be detached from the terminally ill patients. Such a finding suggests that the less death denying the medical caregivers are, the more caring they will be towards their patients. Moreover, Black (2005) found that health care professionals who were accepting of death tended to initiate the discussions about end of life issues with their patients. Her finding suggests that death acceptance enables professionals to take initiatives in discussing important matters with patients. In addition, Liu et al. (2011) conducted a workshop for nurses in which they reflected on their own death attitudes. After the workshop, the authors found that the nurses saw life as more valuable when they confronted their own deaths. By learning that life possesses fundamental value, the nurses became more understanding of their patients’ suffering. In addition, Neimeyer, Fortner and Melay (2001) found that counselors who scored high on a death-acceptance measure also showed greater competency in situations involving suicide. Furthermore, Sinclair (2011) interviewed palliative and hospice care professionals on the impact of death and dying. She found that the participants’ exposure to death and dying led them to be more spiritual and reflect on their mortality. The participants expressed that the study itself gave them the opportunity to explore the meaning of life through their patients. Based on previous literature, I suggest that death acceptance is strongly related to optimal caretaking by professionals (Neimeyer, 2004).

### **Death Acceptance**

I now will turn to a review of the literature on death acceptance. I will define death acceptance as the condition in which a person comes to see death as a less threatening event. In the review, I will start with the quantitative studies and then follow them with the qualitative studies. In doing so, I will show my reasons for choosing a qualitative methodology for this study.

Neimeyer (2004) stated that the empirical findings for death acceptance appear inconsistent. For example, Ray and Najman (1974) introduced the Death Acceptance Scale, consisting of 7 items (e.g., “Death is not something terrible,” “Death is a friend,” “Since you only do it once death should be interesting”). The reliability for the scale was low ( $\alpha = .58$ ). The differences in content among between the individual items may account for the low reliability. For example, the item “Death is not something terrible” implies an attitude that death is not necessarily a bad thing, while the item “Death is a friend” implies an attitude that death is like a friendly person. Although the two attitudes may overlap, one attitude does not *imply* the other. If each item measures a different attitude towards death, the whole scale may be a collection of questions that attempt to measure different constructs.

Klug and Sinha (1987) conceptualized death acceptance as having a cognitive component and an affective component: a confrontation of the prospect of death (cognitive) and a positive reaction towards death (affective). Based on this conceptualization, they developed the 16-item Death Acceptance Scale. However, Wong, Reker and Gesser (1994) criticized Klug and Sinha’s Death Acceptance Scale for its lack of face validity. Specifically, the cognitive items (e.g., “I avoid discussion of death when the occasion presents itself,” “If possible, I avoid friends who are grieving over the loss of someone,” etc.) only measure the extent to which one avoids the topic of death, and it is questionable whether the lack of avoidance equates with confronting death.

In addition, the affective items (“Accepting death helps me to be more responsible for my life,” “My life has more meaning because I accept the fact of my own death,” etc.) only concern the positive influence of death acceptance on life, rather than the affective reaction to death. That is, the measures assess the perceived benefits of death acceptance, instead of how the participant reacts to death. Like Ray and Najman’s (1974) Death Acceptance Scale, Klug and Sinha’s scale seems to measure inconsistent forms of death acceptance. Test-Retest reliabilities were low for both components of the Death Acceptance Scale: for the cognitive component, the  $\alpha$  was 0.59; for the affective component, the  $\alpha$  was 0.55 (Falkenheim & Handal, 2003).

Wong, Reker, and Gesser (1994) devised the Death Attitude Profile, a three-component death acceptance scale that assessed whether one’s attitude towards death is Neutral Acceptance (rationally accepting that death is inevitable), Approach Acceptance (treating death as a step to a better afterlife), or Escape Acceptance (seeking death as an escape from life’s misery). In their study, the authors found that Neutral Acceptance significantly correlated with physical and psychological well-being, and negatively correlated with depression. However, Wong et al.’s conclusions are contrary to those by Wittkowski (1984) and Klug (1997), who found no correlation between positive affects and the “acceptance of death as the natural end,” which essentially seems to be Neutral Acceptance, in Wong et al.’s terms.

Although Neutral Acceptance was one of three components in Wong et al.’s (1994) Death Attitude Profile, Neutral Acceptance itself consists of multiple dimensions. Wong (2008) himself noted that Neutral Acceptance is a broad concept that can mean a wide range of things, from awareness of mortality to completing one’s mission in life. In fact, in Wong et al.’s (1994) original death attitude profile study, Neutral Acceptance had rather low reliability ( $\alpha = .65$ ). Furthermore, Clements and Rooda (1999-2000) found that Neutral Acceptance consists of two distinct factors, one for accepting death as a natural event, and another for accepting death as a value neutral event (neither welcoming or fearing death). Cicirelli’s (2001) study on personal meanings of death deconstructed Neutral Acceptance even further, finding three factors in the variable: extinction (an end of all existence), motivator (an impetus for life achievements), and legacy (an opportunity for one’s accomplishments in life to be recognized by future generations). Hence, as specific as it may seem, these representative samples of quantitative measures seem unreliable. When the construct is ill defined, the measure does not have good validity.

Warren (1983) noticed the difficulty in quantifying death attitudes, as he lamented the contemporary state of psychological science in which a dominance of positivist empiricism replaced the diversity of methodological approaches. He believed that the hegemony of positivism has resulted in excessive popularity in the quantitative assessment of death orientation. The problem, he pointed out, is that the catering to the positivist trend merely gave birth to numerous scales that measured concepts that are unclear or undifferentiated. Moreover, these scales either showed low validity, or their findings are mostly trivial. Even though Warren wrote this article almost 30 years ago, more contemporary authors (Lipsman, Skanda, Kimmelman & Bernstein, 2007; Neimeyer, 2004; Wright, 2003) echo the same concern. From previous studies, the quantitative measures do not seem able to produce useful results. Not only do the measures restrict the extent to which one can elaborate on their death attitudes, they are also inconsistent in their definition of death acceptance. Warren responded to these problems by proposing to depart from the positivist model; he argued that the qualitative, phenomenological perspective is more appropriate for the complex phenomenon of dying.

Turning to the representative sample of qualitative studies, Kubler-Ross (1969) presented the landmark study on how the dying come to terms with death. In *On Death and Dying*, Kubler-Ross interviewed over 200 terminally-ill patients to explore their psychological attitudes towards death. She observed that the dying go through five stages: Upon finding out that they are terminally ill, the dying first go through the stage of *denial*. In this stage, the dying refuse to believe that death could possibly happen to them. The second stage is *anger*, in which the dying acknowledge death, but become enraged by the fact that they are dying. In the third stage, *bargaining*, the dying try to evade death by doing some good, as a child tries to do some “good” to win over a reward, such as candy. The fourth stage is *depression*. In this stage, facing the fact that there is nothing one can do to evade or stop death, the dying feel a great sense of loss. Finally, Kubler-Ross defined the *acceptance* stage as the final stage in the process of facing death. In this stage, the dying quietly await death without anger or sorrow. It is not a “joyful” stage either; the dying simply expect the end of life with emotional neutrality. Kubler-Ross stated that the patient asks to be left alone in this stage as well.

Kubler-Ross recounted doctors’ objecting to her project, telling her to leave the dying alone as the dying do not want to talk about their dying experience. On the contrary, Kubler-Ross’s interviews showed that the dying wanted to share their dying experience. She urged helping professionals and family members to pay more attention to the terminally ill population. *On Death and Dying* exposed the under-treatment of the terminally ill and became the focal point of the hospice movement (Friedman & James, 2008). Since then, the five stages of dying have become household terms among health care professionals and laypeople alike. However, not all theorists agreed with Kubler-Ross’s theory about death-acceptance. For example, Schneidman (1973), from his own observation of terminally ill patients, argued that it is not so much a progression through stages, but an alternation between denial and acceptance. Moreover, the recognition that the “stage” model received also made it liable to misunderstandings; contrary to Kubler-Ross’s intentions, researchers frequently construe the “stage” model to imply that the dying go through all stages in a linear manner, and clinicians pathologize their patients when they deviate from the “appropriate” path through the five stages (Valentine, 2006; Wright, 2003).

More recently, Crossley (2003) conducted a study by following a cancer patient’s diary over the four years in which he suffered from oral cancer. In her study, Crossley found that the patient made sense of his illness through the explicit use of narrative. In the patient’s diary entries, Crossley observed a similarity between his style in coping with death and “therapeutic emplotment,” an act of understanding the clinical condition by construing it as a narrative plot where the therapeutic actions are placed within a coherent story. By writing his reactions in his diary, the patient sought to find hope through the treatment. Typically, therapeutic emplotment is the oncologists’ way of instilling hope for



their patients, by formulating their experiences on a time structure that centers around the present, rather than the future. By focusing on the present, oncologists attempt to avoid a false sense of hope or despair. In Crossley's study, the patient's diary essentially appropriated the form of therapeutic emplotment. From the patients' diary entries, Crossley observed the patient's attempt to focus on the immediacy of his treatment, by writing out the struggle in the treatment and the eventual resignation to the futility of delaying death.

In another qualitative study, Wright (2003) conducted in-depth interviews of 36 participants (12 patients and 24 family members) in a non-hospice setting. Inspired by the influence of Kubler-Ross's "stage" model, and frustrated by the misunderstanding of said model by subsequent critiques, Wright revisited what it is like to be in the process of dying. Based on in-depth interviews, she found that the dying experience was not so much a struggle through stages as a relationship with death. One of her patients spoke of her death as a "grim reaper" that comes to her to attain her soul. Such a metaphor guided Wright into conceptualizing death as if it is a real "person" with whom the dying patient has a relationship. In her framework, her interviews showed six styles of relationships. The first style she saw was *Being Imprisoned by Death*. In this style, the participants saw death as an inescapable presence. One participant, Beth, thought about death upon every action she made. She would go shopping to buy new clothes, and then stop herself from buying anything as she realized that she will soon die. The second style was *Seizing the Day*. In this style, the participants fought to live the remaining life to the fullest. As one participant, Faith, acknowledged death, she stopped her chemotherapy treatment and decided to spend the rest of her life with her loving children. The third style was *Embracing Death*. In this style, the participant integrated their dying process as a part of life. Specifically, one participant, Dawn, spent her time learning about her colon cancer. As she spent her time researching about her dying process, she felt strong for the first time in her life. The fourth style was *Life and Death Transformed*. In this style, the participants found that there is nothing they could do to stop death, and then changed the meaning of life and death all together. Charles, for example, found God as he found that nothing in reality could give him hope. As he found God, death came to have a different meaning. He reconstrued death to mean a union with Jesus. The fifth style was *Silenced by Death*, in which participants stopped talking about death with people. Even though one participant, Noah's condition was deteriorating, he stopped talking about death with his partner who believed that God would save him from his death. Finally, the sixth style was *Waiting for Death*. In this style, participants did not make effort to avoid death, and simply waited for death to come. Patty, for example, found that it is pointless to think what she can do about death. Hence, she simply resigned to the eventual arrival of death.

Wright (2003) found that, while the scientific community asks for the essential "truth" of what it is like to die, the dying process cannot be reduced to generic "stages" or "models." Instead, Wright called for the construal of death as *that with which the dying forms a relationship*, as opposed to *that to which the dying reacts*. She said, "In conversations with dying patients, I was continually struck by how they related with death, as opposed to simply reacted to it" (p. 451). That is, moving beyond the frequent construal of the "stage" model from which the patient can be said to "deviate," Wright argued for construing the dying process as a relationship between the patient and death itself. In such a construction, the observer cannot judge as to which attitude towards death is clinically better than another, as "*relationships* imply a multitude of coping" (p. 452).

Wright (2003) suggested further that each patient had a unique relationship with his or her death; as each patient had a unique life history, the way each of them interacted with the end of his or her life was different. Hence, how one interacts with death may be dependent on how he or she lived life (Graham, Gwyther, Tiso & Harding, 2012; Hirai, Morita, & Kashiwagi, 2003). In this sense, life and death can be seen as connected, mutually influencing each other. Such an account would imply that

the experience of dying cannot be a reductionist account in which an individual's particular life circumstances are neglected for the sake of a unifying model. She concluded that a patient's coming to terms with death cannot be understood without understanding the holistic picture of his or her life and attending to the relationships therein.

In line with Wright's (2003) view, I do not view death acceptance as a generic end-all stage into which all human beings enter when they meet specific qualifications. Rather, I see death acceptance as a process in which participants come to see death as a less threatening event. Feifel (1990) states fear of death is not a "unitary or monolithic" variable. If one's fear of death is unique for each individual, then the process of overcoming death may vary between individuals as well.

Wright (2003) found that one cannot understand the dying process without understanding the patient's life and the relationships therein. Following her study, I determined that a qualitative method is appropriate for this study, as it allowed me to explore the holistic picture of how the dying make meaning out of death, and what their relationships contribute in the meaning-making process. Hence, I conducted semi-structured interviews with older adults who have come to anticipate and accept death. If I had conducted this in a quantitative manner with quantifiable "variables," not only would those "variables" be arbitrary constructions of psychological processes I wish to explore, but I would have lost the holistic picture of the human beings who have shared their stories.

### **Death Acceptance through Experiential Personal Constructivist Psychology**

In this study, I investigated the role of interpersonal relationships in the process of accepting death. My question is based on theorists such as Weisman (1972) who found that the dying have a twofold burden: the intrapsychic burden, in which the dying need to prepare for death, and the interpersonal, in which the dying prepare for their loved ones to be survivors. In addition, Imara (1970) presented a resonant study in which the author found that, in order to reach acceptance, the dying must invest in creating and appreciating relationships with others. Before he started the interviews, the terminally ill patient, Miss Martin, was a difficulty to the nurses that took care of her. Hostile and unappreciative, Miss Martin complained about her illness and put even the most kind-hearted nurse in a bad mood. However, as soon as Imara started the interview, Miss Martin started to change her hostile behavior. Through the interviews, Imara found out that Miss Martin devoted her life to her work, without establishing intimate relationships. As a result, she found herself alone. As Miss Martin met Imara, a person who tried to understand her, she eventually accepted her terminal illness and became a person pleasant to be around. Imara found that to go beyond death denial, the dying have a two-fold commitment; to achieve a sense of their own identity through experiencing their own awareness and to engage in a mutual dialogue.

Based on the agreement between theorists that accepting death involves relating to others, I explored the interpersonal aspect of death acceptance through the framework of Leitner's (1985) Experiential Personal Constructivist Psychology (EPCP). EPCP is based on the assumption that one constructs meaning through the social relation with others. The assumption is an elaboration of Kelly's (1955) Personal Construct Theory in which he asserted that we construct the meanings of our life, thereby building a system of constructs. Within his theory, Kelly introduced the importance of intimate relationships through the Sociality Corollary: "To the extent that one person construes the construction process of another, he [or she] may play a role in a social process involving the other person" (p. 95). Leitner (1985) elaborated on the Sociality Corollary by stating that we make our lives meaningful by sharing our most personal constructs ("core constructs") with others, forming intimate relationships. These intimate relationships are called ROLE relationships (Leitner, 1985) wherein one person comes to understand the construal process of the other.

Turning to death, Kelly (1955) argued that death can threaten our core constructs. Specifically, he states, "If death is incompatible with the construction system through which one maintains a basic

orientation towards events and their anticipation, then the like elements in the context of death are threats” (p.116). In Kelly’s formulation, then, death acceptance would mean that death becomes compatible with one’s construct system. In line with EPCP as well as the previous research above, perhaps one way the dying integrate death into their construct system is through their ROLE relationships. In ROLE relationships, one shares his or her core constructs with other people. If core constructs constitute one’s selfhood, one would be sharing his or her selfhood in ROLE relationships. In other words, in a ROLE relationship, the two persons are no longer two isolated selves separate from each other, but two connected selves. As one cultivates a more relational sense of self through their ROLE relationships, he or she may feel that the legacy will continue through the intimate connections with others. The end of one individual life may become easier to accept, when one becomes more aware of that his or her existence will continue on in the lives of survivors.

In addition to my exploring death acceptance and intimate ROLE relationships, I investigated how the dying invested in their ROLE relationships. How did they express their affection to those whom they love? I do not expect to find an “end-all” answer to any of the questions above. Instead, I wished to see how each participant differs in their answers and whether there are any common patterns.

## **Method**

### **Participants**

In this project, I met with a total of seven participants from South West Ohio. However, I only included interviews of four participants. I excluded interviews in which the conversations did not generate answers that were relevant to my research questions. With some of the participants, our conversations led to tangential topics such as the previous occupation, and previous partners. For example, one participant wanted to focus on her marital problems, making it difficult to see the connections between her death acceptance and intimate relationship. With one other participant, the conversation became more about his profession as a professor and I could not get enough information about his intimate relationships. The “tangents” in these conversations could have implied the degree to which the interviewees tried to evade the topic of death. It would have been interesting to analyze what the evasion of talking about death meant in the context of investigating death acceptance and intimate relationships. However, my focus in this study concerned the content, not the process, of these conversations. Hence, I excluded interviews when the content of the conversations became so off-topic that I became unable to refocus on death acceptance and intimate relationships.

All of the participants anticipated death at one point in their lives. For some of them, death was more imminent to them than others. The youngest of the four participants was a 58 years-old, and the oldest was a 86 years-old. I recruited two of the participants who lived in a nursing home in South West Ohio. I first emailed administrators in a number of nursing homes with description of my research. Once administrators approved my project, I asked them to select participants who were healthy enough to participate in the study. Two participants at the age of 84 and 86 eventually volunteered to participate. I recruited two other participants through a local Episcopal Church. A colleague passed my name, contact information, and description of the study at her local Episcopal Church. On my behalf, she asked for participants who were willing to talk about death. I then contacted those who were individuals with detailed descriptions of the study. I recruited two of them as participants, one at the age of 58 and the other at 66, upon informing them of the full description of the study. I operated under the assumption that, if the participant is already in a nursing home setting, or willing to talk about death, they were acknowledging that their death is imminent to a certain extent. By engaging in in-depth interviews with the patients, I explored how accepting they were of their deaths.

### **Procedure**

In the data collection process, I met with the participants four times: an initial meeting, two semi-structured interviews, and one final member check session. I met participants where they felt

comfortable and had easy access to equipment necessary for their health. For the participants in the nursing home, I met with them in their individual rooms. The participants were able to call a staff member if they needed assistance. However, no such incidents occurred during the course of this study. I met the participants from the Episcopal Church in their individual houses. For one of them, the interview took place in the kitchen. For the other, the interview took place in the living room.

In the initial meeting, I explained the nature of the study and received confirmation that they were willing to participate in the study. Upon my explanation, I emphasized my personal motivation for doing the study by telling them the story of my grandfather's death. The participants then gave me informed consent (see Appendix A). I then set the date for the first interview.

The two semi-structured interviews were structured to the extent that I had a list of questions ready to use (see Appendix B for all questions), but I used it only if the participant was not able to elaborate. In the first interview, I explored the extent to which the participant accepted death. Examples of these questions are "Can you talk about the time you entered the nursing home?" "How are you acknowledging death?" "What does death mean to you?" "How much do you welcome death?" I also explored the topic of the participants' beliefs regarding life after death. I asked questions such as "what will happen to you when you die?"

In the second interview, I assessed how their encounters with death affected their close relationships. Again, I had specific questions ready in the case the participant was not able to elaborate. Examples of these questions are "Who (or what) is the most important person (or thing) to you?" "How much have you known this person (or thing)?" Afterwards, I asked about their relevant stories in regards to the intimate relationships. Specifically, I asked them to recall any story that best characterizes the relationship before and after the acknowledgement of their deaths.

In order to explore the connection between death acceptance and the participant's interpersonal relationships, I asked questions such as "What kind of relationship did you have before knowing about the disease," "What would your [ROLE relationship partner] think of you when you pass away?" or "What kind of story will you leave behind to your [ROLE relationship partner]?" "Is there anything that you would do differently in the relationship?" The purpose in asking these questions was not to promote regret, but to find out whether their interpersonal approach would be any different, now that they know that their relationships will have to come to an end.

As the interviews were conversations, I did not ask each question exactly as I wrote them in the Appendix. Rather, I kept in mind the topics I needed to explore, and contextualized the questions to each participant's story. I recorded all the interviews on a voice recorder. After finishing the interviews, I received help from two undergraduate students in transcribing the interviews based on the recordings (See Appendix C for transcripts).

After I wrote the results section, I met with the participants for the fourth and final time for the purpose of member check. I assessed whether my analyses of the interviews stay true to the participants' experiences. The member check was not an interview; I either read the analyses aloud to the participants, or they read the analyses while I sat there beside them. As they made comments about my analysis, I took note of any corrections that I needed to make, and thanked them for cooperating with my project. All of them said that the information that I had was accurate, but wanted me to clarify the nuances of what they meant. Furthermore, many of them said that participating in the study and reading my analysis was a meaningful experience.

It is obvious that death is a serious and private subject matter, and a graduate student with limited clinical experiences seems to be nothing more than a stranger to such a population. Hence, I was concerned whether the participants would be disclosing to a young stranger about such private matters. However, research suggests that adults are surprisingly receptive to revealing their death attitudes. Studies as early as that of Feder (1965) have shown that, contrary to expectations, the

terminally ill seek to address their dying. He argues that the dying do not fear death itself, but rather the progressive isolation that comes along with dying. Wong et al. (1994) have also observed that the older adults were willing to discuss their attitudes towards death without apparent anxiety. I respected the participants' privacy and asked whether the participants were comfortable sharing the intimate details of their story. In all cases, the participants confirmed that they were comfortable sharing their stories. In fact, many of them told me that they appreciated talking to me about their experiences related to death-acceptance and intimate relationships.

### **Analysis of the Interviews**

Wright (2003) held a perspective that, in order to understand someone's death, the researcher needs to analyze it in the context of that person's particular life. In the spirit of Wright's perspective, I analyzed the data on a person-by-person basis. For the analysis, I used my recollection of my experience with the participants, the audio-recordings of the interviews, and the transcripts generated by my undergraduate assistants. In analyzing each person's interviews, I found a unique story of how each participant became accepting of death, and how his or her intimate relationships played the role in the process.

Below I present each participant's story in enough depth so that the rationales of my analyses are clear to the readers. Each participant's story is divided in three sections. First, I present a general description of the participant as well as first impressions relevant to the topics studied. Second, I present the participant's past and current attitudes about death and relevant stories. Finally, I provide the history of their most important relationship, and how it changed in relation to their attitude towards death. I present the findings on the way the participants' process of accepting death, and the evolution and the contribution of their intimate relationships by quoting relevant parts of the interviews taken from the transcripts, and offering my interpretations afterwards.

## **Results**

### **Brian**

**Brian's Story.** Brian is an 84 year-old Caucasian male who has been residing in a nursing home for the past seven months. As I entered Brian's room, I first noticed a series of pictures. In some of the pictures, Brian was dressed as a Boy Scout Ranger, smiling with young Boy Scouts. Other photographs included Brian with his family. During the interview, he often pointed to these pictures, introducing me to his family and friends. Knowing that I am Japanese, he often spoke of the Japanese Boy Scout who worked with him. His name was Takuya. Brian said that I remind him of Takuya. I was not bothered by this association; it was clear to me that Brian was fond of Takuya, and I never felt uncomfortable. Brian never made any off-putting remarks, and, if anything, he seemed interested in the difference between our nationalities.

In fact, I liked Brian the moment I met him. He greeted me with a disarming smile, and seemed happy to talk about his experiences. As I told him about the procedures of the interviews, I found it easy to tell Brian the story of my grandfather's death. I disclosed to him my personal importance of studying death, and Brian nodded firmly. He agreed that death was a very important topic to talk about. I noticed that Brian could not stop shaking when I gave him a pen to sign the informed consent. In response, Brian sheepishly told me that he had Parkinson's disease. I would soon find out that his Parkinson's disease and death have had a long-term relationship with Brian.

**Brian and Death.** Brian first gave a general description of his life in the nursing home. He then talked about a time when he went to a county fair with his fellow residents. At first, I thought Brian's story was going off-topic. The beginning of the story seemed too sudden and different from the conversation that preceded it. However, I soon became clear on its relevance, when Brian said that he felt his Parkinson's was kicking in. The story about a joyful trip soon turned into a story about yet another instance of Brian's struggle with Parkinson's – how a day trip to a town fair can turn into a

struggle between life and death.

**Brian (B):** *Wednesday we went to the county fair in Butler County. And they-they wanted me (laughs) to go. And I said, "You sure you want me to go? I may not be able to go-uh, take it." You know? And they said, "Yeah we're-we-we'll be with you. We want you to go." So...*

**Aki (A):** *Who was it that was inviting you?*

**B:** *That was the activities lady. And um, so we got in the van, and we went to the county fair. And got on the highway, and we didn't have any air. And the air conditioner wouldn't work. And I said, "Oh my Lord." So it got pretty bad, and then the fumes from the exhaust started coming inside, and I can't take fumes. So yeah, we pulled off and let the one boy got sick. They let him get out and walk around a little bit and put him back in. I said, "Let's go on. Let's go on." So we went on. We went to the county fair. We got down there, and it was so hot. And we were in wheelchairs. They were pushing us in wheelchairs down through the fair ground. And we didn't get to see much. We didn't get to see much. We went all the way down to the arena, where the seats were for the racetrack and everything. And we sat there and rested a while, and she decided we better go back home. So...we started back. They went and got the van where we unloaded at and brought it up there, and we loaded up, started back home...And it overheated. We had to pull off. And they had to call for help. So we got the mechanic here. He came down and- and then one of the office ladies brought a Cadillac that the company owns here. And I was getting bad. The Parkinson's was kicking in, and I was overheated. And um, they had cold rags around my neck and on my face, and- and I thought, "Oh boy. This is going to be a mess." But they put me in the- in the Cadillac and brought me back. And they brought me and put me in this chair. And then I had one of my spells. I was out of it then the rest of the evening. But uh-I- I made it. I made it.*

I was curious as to why he described the event in such detail, after a rather general description of his life. As I pondered what led Brian to share a detailed story, I thought about Leitner and Guthrie's (1996) guidelines for assessing client's validation and invalidation of interventions. Specifically, they argued that sharing important new material was a sign that the client validates the therapist's interventions. While my interactions with Brian were hardly clinical, I thought that there was a reason why he was sharing his story. I then remembered that he was sharing the story of his struggle after we started our conversations about death; the fact that he shared so much seemed as a validation to talking about death in further detail.

From listening to Brian, I soon found out that struggling with disease and death have been closely intertwined throughout his life. In his childhood, death horrified Brian.

*I've seen a lot of death in my life. And when I was a young boy, it scared me to death. We would go visit people that were dying. And uh I would come home, and I'd have nightmares, you know, at night. I had seizures when I was eighteen years old. And all the way up until 1986. At nineteen, I had been in the service, and I had seizures when I was in the service. And uh, when I'd come home, (pause) I still had the seizures. 1986 um, I got rid of the seizures. The seizures quit on me.*

Here, Brian makes clear how seizures were simply a part of life. He experienced seizures whether he was in the service or at home. The fact that Brian rephrases the sentence "I got rid of the seizures" (in which Brian is the active subject) to "The seizures quit on me" (in which Seizures is the active voice) spoke to me about how much seizures took control of his life. However, I soon found out that his struggle with a disease was not entirely over. Even after the seizures, Brian was struggling with a disease nonetheless, in a different form.

*And so they said, and at this point I had open-heart surgery. I had a stroke. And then after the stroke, I had open-heart surgery. And when I had open-heart surgery, then I started this here*

*Parkinson's. I started shaking real bad.*

In the form of Parkinson's, Brian's construction of disease continued in a different form. Brian's construction of disease, seizure and Parkinson's were in the same category, as he said that one of Parkinson's symptoms was passing out, which he said was "*almost like a seizure.*" He elaborated that Parkinson's is a longer-lasting, worse form of seizure. Brian was not the only person who suffered from the disease. The disease ran in his family.

*And I don't know really what caused the- the Park- of course my family, it runs in my family. My dad had Parkinson's, and my two brothers had Parkinson's. They both died with Parkinson's. And uh, I had two sisters that had Parkinson's. So it kind of runs in the family.*

At this point in the interview, the scope of the Parkinson's became much larger than it had been at the beginning. Not only was the disease present in Brian's life, it also haunted many of his family members as they died. As soon as I heard that many of Brian's relatives died of Parkinson's, I asked him whether death reminds him of Parkinson's.

**A:** *Um, so you said you're relatives- your father um, they died- died of Parkinson's. Um, does having Parkinson's remind you of um, death?*

**B:** *Yeah. Uh, because my uh, knowing that my dad died, he had it. And uh, my uh, (pause) one brother, one real older brother had it real bad, and he died with it. And I stayed with him, and you know, watched him go. And my other brother, he got it, and he was real bad. He was ninety-one. And they had to strap him on the bed. He got so bad that he was like me. He- he had fighting in him, you know, where you fight yourself. And uh, they had to strap him down. He lived in North Carolina. And they had to strap him down in the nursing home- he was in a nursing home. And uh, he- he finally died. And so, my two sisters had it, and both of them died. And uh, but they didn't have it that bad. They didn't have it as bad as what I've got, or what my one brother had. But it uh, it bothers you. Um, course I- I- I really am not afraid of death myself because I'm a Christian. And- and I believe in God. And uh, I put my faith in God.*

Brian told me earlier that he was threatened of death as a child. However, Brian told me that he became unafraid of death because he had found God. In fact, even before the interview started, Brian told me that he was not afraid of death because he was a Christian. In the beginning of our conversation, I nodded thoughtlessly to Brian's declaration that he was not afraid of death. I felt simply glad that Brian was forthcoming about the subject matter that I sought to study. I had not yet thought about how being a Christian meant not being afraid of death. It dawned on me, however, that becoming unafraid of death involved a profound and personal experience for Brian. Brian experienced a moment where his life long struggle with disease intertwined with his other passions of his life, such as his family. This experience was Brian's closest encounter with death.

*Doctor took me out, made me retire....And that hurt me so bad that I had to retire and quit my job because I loved my job working with Boy Scouts... But anyhow I was sitting on my front porch one day, and there was just like something that spoke to me: "Get up, and get in your car. And go down the road, and hit the biggest tree you can find. And you end it all. You won't ever have no pain no more. You can end it all." And you know I got up and got my hat. I wouldn't go nowhere without my wife, but that day, after I heard this voice in me, I got in my car. And my wife said, "Where are you going?" I said, "I'm just going around the block." And I went out, I went down the highway, and I turned on a road. And I went to this one crossroad. And I pulled in that crossroad. I could not hold that steering wheel. I could not, I could not guide that steering wheel. And I backed out on the road. I went back, right like I came. And I said to myself: I said, "What in the world am I doing?" And I went straight to my sister's house, pulled up in her driveway. She was standing in her door and looking out. And I pulled up and got out. And she said, "Brother, come in here." She said, "I've been praying for you all day." And so I*

*went up and hugged her. She said, "You're going to church with me tonight." And I said, "Well, I guess I will." She said, "You go home and get dressed up, and we'll pick you up and take you to church." And so I went to church. And that night, I got saved.*

Brian's story revealed an important moment about his Christianity. As I found Brian's story to be touching, I realized that accepting death was far from just an intellectual theory within Christianity. It was Brian's personal, experiential truth that he found after struggling to end his life. Ever since that evening, Brian has been a Christian, praying to God, thanking him that he had found a new meaning in his life, which was to live a good life according to the words of God. Death did not haunt him anymore. Brian said he became a "different creature" since the event.

While Brian may no longer be afraid of death, he told me that he worries about other people who fear death. As he is surrounded by people who express death fear, he said he tries to relieve others of their fears. Specifically, he attempts to pass on his Christian faith to others, saving others from the fear of death. Brian said that his good deeds grant him entry to heaven, where he will be without sorrow or pain. Listening to Brian, I received the impression that he enjoyed the act of helping others. Brian told me proudly of the time he had another nursing home resident smile at him by telling her that he loved her, when no one else could.

*And I tell everybody, you know, once you- once you get born again, that's what the Bible says, once you get born again with the Spirit, uh, you don't have to fear death. Uh, and uh, it- it'll take that all away from you. So (pause) I tell the people here, you know, there's people here that's bad, real bad. And uh, I've been just showing my pastor, uh come and go while I was eating lunch. And he came, and uh, the lady was sitting down the end of the table there- she's got that Alzheimer's. And she's real bad. She's real bad. And they couldn't get her to take her medicine. And they couldn't get her- she'd fight them, you know- "Get away. Get away," and curse them out and everything. And I told my pastor, I said, "Watch." And I went down to her, and I- I talked to her and got her talking to me. She called me by my name. And I said, "I love you." And she said, "I love you too, Brian." So see, it's- it's- it's just a way God uses you. And uh, I- I- I'm just so grateful that one day that the Lord saved my soul, you know.*

Although Brian was proud of the times he helped others find comfort, he also talked of painful times he lost his loved ones. One of the most painful losses was the death of his oldest son. Brian told me that he tried to save his oldest son a while before his death, as his son struggled with a drug addiction. Although Brian tried his hardest, he could not change the course for his son from the grip of addiction and death. His son eventually quit taking drugs, but was selling drugs to make a living. Soon after, a motorcycle accident took his life. Brian gave credit to God for helping him cope with grief.

Another loss pertinent to Brian was the death was of his wife.

**Death-acceptance and Intimate Relationships.** When I asked Brian about the most important person to him, he quickly answered that it would be his wife. They were married in 1951, and lived together for 44 years until she died from cancer. They raised five children together. He also told me that she was of Indian descent. He started talking about so many of her relatives – parents, grandparents, and siblings. He recounted in detail how they died. He told me that he lost his wife, mother-in-law, and brother-in-law in a very short span of time.

I asked him about their first encounter. *"It was a mystery. It was something strange,"* he said. He said that he was convinced upon first sight: *"Boy, there's my wife."* He said there were many girls who were interested in him at the time, but he was not interested in any of them. However, there was something different about the girl who would be his wife. For unknown reasons, she stood out from the rest of them. One day, in another whimsical encounter, he acted upon impulse:

*That Saturday night, I- I'd been in a theater- to see a movie, and I came out, and her and this girlfriend of hers, were walking down the street behind me. And then I- I heard them laughing,*



*and I turned around, and it was her. And uh, so I stopped, and I said, "Hey." I knew her girlfriend- I knew her. And I said, "You girls want to go down and have a- a cony dog and a root beer with me?" I said, "I'll buy you a root beer and cony dog." And they said, "That sounds good." So we went in the little restaurant. And we had the- I got them a cony dog apiece and- and a root beer. And we sit there and- and chattered. And I asked her for a date. And it embarrassed her. And uh, I said- well, I said uh, "You can say yes or no." And- and uh, I said uh, "Would you like to go to the movie with me next Saturday night?" And she said, "Yeah." We met, and we started going together. And we went together a long time before we got married because I wanted her to grow up. She was only sixteen years old. And I wanted her to grow up. I didn't want to marry her right away.*

After a detailed account of how he won his first date, he summarized the rest of their marriage: *"And we got married, had five children."* I got the impression that Brian was simply very happy with the way the relationship turned out with her.

*The other girls that tried to get dates with me, I watched them all get divorces. They married and got divorces. Her and I never did get no divorce. We stayed together. And we lived...we didn't live rich or anything like that. But we lived good.*

It was clear that Brian was happy and believed he made the right choice in the person with whom to spend the rest of his life. I asked him about the role that she played in his life. Brian sheepishly told me:

*She was just everything I wanted. And she was a good cook. She was just a good person and a good mother. She took good care of her children. And she was a good housekeeper. And just everything I wanted in life.*

Brian seemed to appreciate his wife for many reasons. His affection for his wife was such that she meant "everything" to him. At the same time, Brian said they still had their space from each other. *"If she wanted something, she'd go and get it. And if I wanted something, I went and got it. So we played together."* I wondered whether Leitner's (1985) concept of ROLE relationship applied to Brian's relationship with his wife. Leitner (1985) stated that, in ROLE relationships, there still needs to be a certain level of mystery between the two people. As Brian talked about the space that existed between him and his wife, I started to think his relationship with his wife may be a ROLE relationship. However, I was still unsure about the depth of the relationship. His descriptions about his wife, so far, were too general for me to conclude anything.

I got a better glimpse of the depth of the relationship, as Brian started talking about how his wife took care of him in his ailments. Brian said that his wife had been there for him when Brian had suffered from his strokes and seizures. In ROLE relationships, intimacy requires the continuation of relationship despite the change (Leitner, 1985). Through hardships, Brian recalled vividly the times his wife took care of him as he experienced the seizures.

*And she was just really good to me. And uh, I tried to be the same way with her. But back in uh- '69, 1969, I was a ranger for Boy Scouts. And one- one day I was in the workshop working, and I had uh- uh- the camp director come in and said, "Hey Brian. Let's- let's go to lunch. It's lunch- it's twelve o'clock. And- and they're having lunch up in the dining hall." Hes said, "Let's go to lunch." And I said, "Okay." And I walked out. And I got a pain in this shoulder here- a real sharp pain. And went through just like somebody shot me a bullet, you know- went through. And and I started to my truck, and he said, "Come on. Where are you going?" I said, "I got to go home. Something's wrong." And so I got to my truck. I tried to get up in my truck, and I had a hard time getting up in there. And I was getting weak. And I thought I got shot. I thought somebody maybe shot me. And I got in my truck and started it up and went over to my house and pulled up in the driveway. And I stopped and got out and went to the door.*

*And she comes to the door and she said, "What's the matter with you?" She said, "You look funny." She said, "What's the matter?" I said, "Get me to the hospital." I said, "Something's bad- wrong. I think I've been shot." And she said, "Oh my goodness." And she went out and got in my station wagon, and she went over. And she got the camp director. And uh, she said, "Something bad wrong with Brian, and we got to get him to the hospital." So his wife was a nurse there- at the camp, and he told her. He said, "Call the hospital, and tell them we're on our way." And uh- so they put me in the station wagon, and he comes to the house. And they got me out and laid me and put me in the station wagon. She sat in the middle, and I sat on the outside. And and we got here in Oxford coming in the first stoplight. And he drove- she told me that he drove ninety miles an hour all the way just flying, you know to get me there. And uh, with the lights on and- and everything. And when they got to the stoplight, down flooring it- coming in, she said uh- uh, he had to stop. The light was red. And he honked the horn down. And she said I just fell over. And she said she told him- said, "He ain't breathing." She said, "He ain't breathing." She said- so he speeded up and got on up to the hospital. And he come around, and she said the nurses were out there with a wheelchair to take me in. And he kicked the wheelchair away. He said, "No." He said, "He ain't got time." And he just picked me up. And I was pretty big. And he was tall, slim guy. And she said he just picked me right up in his arms and run in the hospital in the intensive care unit. And my family doctor just happened to be coming down the hall. She said, when the one woman was calling bl- code blue. And uh, that's emergency. And so he took me and put me on the gurney and said that doctor come- know when- they called that- and he came in the emergency room. My wife said he checked me and told- said, "Get me the paddles." Said, "He's- he's gone." Said, "Get me the paddles." So he used the paddles on me... But uh, he brought me back. And uh- uh one of the housekeepers there- one of the- one of the, hospital cleaners was a friend of mine, and she was there in that room cleaning, and she watched them. And she told me later that uh, it took them about forty-five minutes to get me back uh, normal. And get my- and he got my heart beating again and got me back. And uh, so I stayed- they put me in intensive care. I was in there uh, two weeks- intensive care. They had me on an oxygen tank with uh- they give me oxygen. And uh, but I survived. I survived.*

Brian was in no mental state to be aware of his surroundings to such detail. At one point, he was not even breathing. In such a state, it must have been difficult for Brian to recall the story first-hand. In fact, Brian's recollection is a collection of "she said..." "she told me"; It was only through his wife that he was able to tell the story. Furthermore, Brian remembered that his wife was simply there for him, after all the physical pain.

*Yeah. And...she was there one night- I was there- they kept me out five days. And I didn't know anything. And then when I come to that- the fifth day- uh- that fifth morning- at ten thirty- she was sitting in my bed. Uh, my wife was. And- and uh- I- she stuck with me.*

Brian's recollection of finding his wife on his bed led him to remember that she was with him in other instances when he needed medical attention. "She stuck with me. Same way when I had the stroke in '79. She gave me therapy and stuff. We really...I really couldn't have found a better wife." Brian's memory about his wife upon his hospitalization was not an isolated instance, but an event representative of their relationship. In their relationship, his wife was always there for him whether he was sick or healthy.

Throughout the interview, Brian frequently mentioned how much he missed his wife. The more he talked about the life that they had together, the more he was reminded of her death. Kelly (1955) stated that our constructs about the present moment are connected to our constructs about the future. However, facing death leads to a disruption in the continuity of our relationships. I was curious as to

how Brian dealt with his wife's ailment, as it must have disrupted the relationship that Brian envisioned. Brian spoke to me about what he did as she suffered from her cancer.

*I missed her so bad uh, when she took cancer- passed away. But I stuck with her. I stuck with her sixth months. I- I- I sit right beside that bed. And when I had to take her to the hospital, I go in that hospital and stay right there until they let her out. I stayed right with her. And uh, I didn't get much sleep. I- I went down, and I had heart trouble too at that time.*

As his wife stuck with him through his ailments, Brian stuck with her through her death. Brian reciprocated what his wife had done for him for the past 45 years. In doing so, however, Brian felt a sense of shock. Brian's heart-trouble and lack of sleep spoke to the emotional pain he felt as his wife suffered from cancer. Leitner and Faidley (2006) reminded us that the separation between the mind and body is only a construction, Brian's physical and emotional pains both seem to represent Brian's difficulty in responding to his wife's death. He told me that he received medication from his doctors in order to take care of his heart problems. He also sought consultation from God.

*And I'd pray, "You- you got to help me, you know. You got to help me go through this." And uh- and He did. He helped me, and I made it. But uh, it- it was hard- it was hard to go through that. And uh, I know uh, when she was in a coma- before she passed away, she told- uh- before she went into the coma, she told me- she said, "I want-" Said, "I know I'm going to die." And said- said, "You- you don't live by yourself. You get you another wife, and don't live by yourself." But I could have never gotten me another wife. I could never replace her. And I know there are good women out there, but I couldn't ever. I just couldn't. In- in my- my thoughts of her, I just couldn't.*

Brian told me before that God and Christianity had helped him accept death. Here, it seemed as though God helped him accept his wife's death as well. However, his acceptance of his wife's death did not seem to mean an end in his relationship with his wife. On the contrary, Brian indicated that his relationship with his wife still continued. As Brian said that he could not find another woman, he indicated he left a space in his heart for his wife. God's help in accepting his wife's death, hence, did not mean that He helped Brian to let go of his relationship; it simply meant that He helped Brian accept her departure. Brian's statement below confirmed of his ongoing relationship with his wife:

*Uh, it's still- still dreadful. It still hurts. And uh, yeah I think about her all the time. I keep her pictures up on the wall here- right up here behind you. And uh- uh- yeah. But uh, I can't do nothing about it, you know. It's just something the good- good Lord done. And uh, everybody has to die. So- but uh, I didn't want to see her in that shape no more. And I- I- you know- she's- she's not in pain no more. And uh- oh I- it- it's hard telling how much pain she went through. And uh, yeah.*

Brian cried as he spoke. By having her pictures around him – watching them, showing them, introducing them to other people – Brian was continuing his relationship with his wife. Still, he acknowledged that death was an inevitable event for his wife. He hoped for his wife to be relieved from her pain than to continue to suffer any longer. To Brian, it was a matter-of-fact acceptance that she was dead, but his relationship with her was alive and ongoing, with all the emotions involved – the pain of knowing that she is gone, and the joy of remembering a precious memory.

It was evident to me that he shared a deep relationship with his wife when she passed away. I wondered how the relationship changed over the years. Specifically, I was interested in how his relationship changed as his attitude towards death changed. For Brian, the turning point was clear. In the first interview, he stated that he became unafraid of death when he became a Christian. Brian became a Christian when he contemplated to kill himself.

As I asked him about the day he became Christian, Brian first reminded me that his wife was always there with him. He acknowledged his wife's support: *"She gave me therapy and helped me all*

*the time I had that stroke and really brought me out more than what the doctors and things did.”*

However, Brian acted differently when the voice in his head told him to drive into a tree:

*Well that day, whenever uh- whenever that- I- that voice spoke to me and told me to do that, and I got up and got my cap, she knewed something was wrong. And she said, “Where you going?” And I- I lied to her. I told her- I said, “I’m just going around the block.” I said, “I- I’m just going- you just don’t worry about me. I’ll be alright.*

Brian wanted “that voice” to be hidden from his wife. I asked him why, to which he said, “*I didn’t want her to worry about me I guess*”. Interestingly, Brian thought that his wife knew there was something wrong with him. However, he seemed not able to tell his wife about his contemplation about suicide.

Later, when he found himself unable to drive into a tree, he realized the absurdity of his thinking. Rather than driving himself to death, he chose to live the life of a Christian. As he decided to continue his life, he found his new purpose of helping others in his life. He confirmed the importance of connecting with others, as he said:

*Ever since that day I’ve been a different person. And uh- yeah I- (pause) that’s what makes me- that’s what makes me go out here and associate with these poor people out here- it’s bad awful. And try to help them, you know.*

In the above statement, he elaborates further on his turn to be a Christian, that it makes him “associate with these poor people out here.” Hence, his turning Christian led to his helping others. Of course, the most important person in his life was his wife. I asked him whether his relationship with his wife changed after he was saved from driving himself to a tree:

**A:** *You said you became a different person- the way you looked at your wife- did that change?*

**B:** *(pause) Yeah.*

**A:** *How so?*

**B:** *Just- just made me love her that much more.*

**A:** *That much more?*

**B:** *Yes, that much more. (pause) Yeah. My wife- my wife was just- she was just a part of me- that’s all it was. She was just part of me. And she cared for me just like I cared for her.*

Through his transformation into a life in which he “associates with” other people, he stated that his love for his wife grew more intimate to the point that she became a part of him. From his statements, Brian seems to establish the following relationship between accepting death, turning Christian, and helping others: as he almost encountered death by driving himself into a tree, he experienced an identity change in which he became a Christian. Becoming Christian led him to appreciate the connections with people (“go out there and associate with others”). In his deepening appreciation for other people, his love for his wife grew deeper as well. Tellingly, during the interview, talking about his wife's death led Brian to both smile and cry. His expressions seemed to represent his relationship that was characterized with the joy of relating to someone and the pain of losing her. As his relationship with his wife deepened, he seemed to have become less afraid of death. As he said “I am not afraid of death, because I am a Christian” in the beginning, his death acceptance was associated with his newfound Christian faith, and the subsequent deepening of his relationships.

In summary, Brian became less threatened by death as his relationship with others became deeper. In his earlier days, his diseases reminded him of death and threatened him. He became less fearful of death when he became a Christian. The change in his identity was facilitated by a moment where he contemplated driving himself into a tree. Through this event, I found that contemplating death brought a comprehensive change to his identity as a Christian. In the moment he became a Christian, his appreciation for others also deepened, the most important of which was his wife. The reciprocity of being with each other through difficult diseases characterized the depth of his relationship with his

wife.

**Member Check.** After writing the above section, I took the writing to Brian for member check purposes. Brian requested that I read my analysis out loud to him. Given that I was reading the printed sheets of paper, I did not see Brian's face. I only heard him say “mmhmm” and “uh-huhs,” affirming what I wrote about him. It was only when I finished that I was finally able to look up in his face. I noticed that Brian was shedding tears. He affirmed that my analysis was a truthful account of his death-acceptance and intimate relationship. Everything that I had written was accurate to his experiences. He thanked me, stressing that he was blessed to have met me. He joked that he would give me a “100” if he were my professor. In tears, he told me that it was the best thing that happened to him in recent years, and that he would never forget me or my project.

### **Tammy**

**Tammy's Story.** Tammy is a 58 year-old Caucasian female who currently lives with her son, Kyle. Tammy retired one year ago. She reported that she is very happy with her retired life. For the interviews, I visited her in her own house. While the interview took place in her kitchen, her son was studying in a nearby room. I asked her if she was comfortable doing the interview with the son in a room close enough to hear our conversation. Tammy reassured me that she felt comfortable. I realized that the proximity and comfort between Tammy and son was representative of their relationship. Although Tammy said that she would like to stay in Oxford as long as possible, she said she may move if her son decides to move elsewhere after graduation. Sandy said that she does not necessarily want to live with him forever, but simply live in a house that is closer to his. As I explained that I will asking her about her thoughts and experiences with death. She assured me that she is willing to talk about death, but warned that she will become emotional. I said that there is no problem with her crying.

**Tammy and Death.** As we started talking about her life, we naturally transitioned to the topic of death. As I explored more about what she plans to do with her life in the future, she answered:

*I would like to be able to be independent and to be able to live on my own as long as possible. I really don't like the thought of having to be in a nursing home setting. I know that facilities are certainly improving and care has improved over the years, but I don't know. To me, that is probably the thing that gives me the most discomfort is the thought of having to be long term in a nursing facility.*

So, Tammy already was thinking of a future in which living in a nursing home was one undesirable possibility. The fact that she brought up a nursing home made it easy for me to bring up the last stage of her life. As she emphasized her dislike of nursing homes, I was particularly intrigued where such dislike comes from. I inquired further about Tammy's dislike towards nursing homes:

**Tammy (T):** *Um, I guess, you know if I had a private room it probably wouldn't be that bad. It would be having to share a room with somebody else and feeling, I think feeling like I had to be on my best behavior all the time because somebody else was there or something like that.*

**A:** *Being watched...*

**T:** *Yea, yea. And the feeling, I think I would feel like I was a guest in somebody else's home type thing. Home isn't the right word. I mean because, this is my home and I can do what I want and whatever schedule that I want but I guess I feel like if I were in a nursing facility, its not my home and I would feel not- like I didn't completely fit in because its not my place.*

Tammy was discussing a core value that would be important to her: namely, the concept of home. Although she struggled with the appropriateness of the word “home,” she continued to use the word to articulate her concerns. From the last sentence, I noticed that “fitting in” is a key construct of where she wanted to be in the last stage of her life. As I asked her whether it was because she did not own the place, she corrected me: “*Um I don't know that its ownership as much as sense of belonging.*” Although I was mistaken in assuming that a sense of ownership mattered to her, the importance of

“fitting in” was confirmed further as she emphasized the sense of belonging.

After the discussion about the sense of belonging, I asked her how she felt about death. Tammy seemed comfortable answering my question:

*Um, I was with somebody once and we were talking and I can't remember ever being afraid of being dead. Death itself does not really scare me. The process of dying is a different thing. And it was funny because this other women felt exactly the opposite. She wasn't worried about the process of dying but she couldn't handle the concept of no longer being alive, no longer being in the world. And, for me, I would love to just fall asleep and not wake up and never feel any pain or discomfort. And that would be a beautiful thing. It's a beautiful way to go. I think I've always kind of felt that knowing that life didn't, this physical life didn't go on forever made it more precious. That you should try to appreciate and enjoy it and make the most of it because it wasn't going to last forever. I grew up Roman Catholic and I'm now in the Episcopal Church so I'm pretty sure that the idea that there is a life after death has probably made that easier for me. The idea that yes my physical body will end but something will continue.*

Tammy made clear that she distinguishes death from dying. The former is simply the end of “physical life” or “no longer being in the world” whereas dying involves the “pain or discomfort” that comes from exiting this world. Furthermore, as she specified that the “physical” life does not last forever, she seemed to make another distinction between non-physical life and physical life. In other words, for Tammy, death meant the end of her physical life. She is not fearful of the cessation of her physical life; on the contrary, the end of her physical life is what makes life precious. Her belief is reminiscent of Heidegger's (1967) assertion that accepting death is a pre-requisite for an authentic life. However, Tammy's beliefs about death seemed more complicated than what can be reduced to Heidegger's philosophy; she wondered whether not being afraid is easier because she subscribed to the idea that that there is a presumably non-physical life after death. In other words, her lack of death fear may depend upon her belief in an afterlife.

As we explored more of how a non-physical life can exist beyond death, Tammy shared her recent musings about the form of such an after life. After hearing from a neuroscientist on NPR that the mind cannot exist without the brain, she wondered about such an implication for the soul. She wondered whether the soul that survives the death is an individual soul, or a soul that conjoins with God, thereby ceasing individuality.

I should point out the theoretical tone of our conversation as we discussed Tammy's distinction between the mind and body. Tammy was talking more about her intellectual beliefs, rather than her personal experiences. Given the conversation had departed from a more personal opinion about the fear of death to a musing about after-life theories, I wondered how important these theories were to Tammy.

*I used to have the idea of- of course I was raised with the individual soul idea. And then when I was thinking about this brain-mind thing I was thinking about how in the tradition that I was raised in there's the belief in the resurrection of the body. At the end of all time that your body will be brought back. I thought, well if you're going to believe in an individual me continuing to exist as the individual that I am now, you would have to believe in the resurrection of the body. But, um, there's also a part of me that thinks it really doesn't matter (laughs) because when I'm dead, you know, if heaven is true, if an afterlife is true, if my body is resurrected is true, well that's wonderful. But if its not, it doesn't matter.*

I was unsure why she laughed. Perhaps, she felt anxious about the thought of her dying. It seemed as though there was something more to her feelings about death than the theories she was explaining. Rather than her intellectual discussions of death, I started thinking about the emotional aspects of death. Tammy said earlier that she did not have any fear of death. However, as she warned me that she will choke up during the interview, I suspected there had to be an evocative story that

involved death. As I asked her about her feelings towards death, Tammy said the following:

*I think because I've always pretty much, I mean I still have that tendency to believe that my soul will continue on. So I don't think that I've had a fear level about death. It's more an intellectual change than an emotional change that I would say. I mean nobody likes the thought of dying and certainly, you know if, if you get into a situation where it's dangerous of course I'm going to react at that time. But to sit and think about it, I'm certainly more distressed at the thought of my child's death. That, there I'm getting choked up already. That would disturb me but my own does not except for the concern for those that are left behind. I lost a brother eight years ago and he died very suddenly and unexpectedly, a heart attack and um, the most difficult part of that experience was watching my parents go through it. And so for me, that is the only distressing thing about dying would be knowing that the people that would be left behind would be suffering.*

Tammy seemed to exhaust the possibility that she was ever fearful of death. However, her demeanor suddenly changed as soon as she started thinking about her son. I noticed that the moment she started crying was the time she shifted her attention from herself onto another person. I wondered whether Tammy was bothered about death not so much for what will happen to her, but for how it may affect other people. As she thought about those whom she would leave behind, her tone towards death changed and became more emotional. In contrast to the theoretical musings, her thoughts about another's death were personal.

She explained that her brother was the oldest son of her parents. It was especially hard for her father, given that her brother was named after him. Tammy commented that her parents never expected to outlive any of their children, so her brother's sudden death was shocking. As her parents are still alive, Tammy felt a special responsibility not to cause them further distress. She expressed her determination as she said, "*No matter what I do I've got to at least outlive my parents now.*"

Her parents were not the only people she was worried about. As Tammy started crying as she thought about the death of her brother, she also worried about her son. She told me straight away when I asked her who she is most concerned about as she thinks about her death.

*Of course my primary concern is my son. His father died seven years ago now, they were estranged at the time of his father's death. And they had not been close for awhile. But I do worry about him and I am the only parent he has right now. He doesn't have any brothers and sisters. He's got a half brother and a half sister who are much older. They're the same age as some of my brothers and sisters. His father was 16 years older than I was and they've not been close, they've not lived in the same town. My brothers and sisters, his aunts and uncles and his cousins don't live here in the same town. He gets to see them pretty often and I think he's pretty close with some of his cousins, but he's going to be pretty much on his own when I pass away. He's been through, he's lost grandparents, his father, his uncle. So he's been through the experience. I know he doesn't have the same faith beliefs that I do. I know he believes in God but I don't really know how much of a comfort, a religious ceremony or faith will be for him so that's a concern about where he will find the support. I know he's got friends, he's got some family support. So that's a concern. I already talked about not wanting to put my parents through losing another child because that was very difficult for them.*

A theme of loss was prominent in Tammy's statements about her son. Kyle's life seemed to be characterized with distance from his family members, and many separations from his dying relatives. It was clear that she tried to see what his life would be like without a mother. Tammy was reminded of her role in his life as she enumerated relatives who were distant from her son over the years. Seamlessly, the theme of separation turned into the number of deaths Kyle endured in his life. As themes of separation and death interwove together, I came to have a clearer picture of how death

distressed her: death distresses Tammy for the loneliness it causes others. Although she found her Christian faith helpful in her own grieving, she worried whether faith will be helpful for her son.

It sounded as though she was concerned more about what happens to others rather than her own dying process.

*A: Are you more worried about how others will respond to your death rather than what happens to you when you die? Does that make sense?*

*T: Yes. That really is, because when I die, you know if I'm right and there's an afterlife, I will be fine. It's like when my brother died and I said I know that we aren't crying for him because of our faith- Christian faith. We believe that he is with God. So I'm not crying for him, I'm crying for us. And so you know, I do believe that somehow or other my soul will continue. I will be either in the presence of God or one with God. You can't beat either of those options as far as I'm concerned. And like I said if I'm wrong, and I'm gone, it's not gonna bother me. I mean, when you're dead, if all there is when you're dead is nothing, it's not going to affect me. And I can accept that. So yea it's more of a distress to me what happens to other people.*

As Tammy talked about her late brother, she emphasized the importance of her Christian faith. Her faith allowed her to not worry about her brother, as she believed that he was with God. She was not worried about herself dying; she believed that she would be with God as well. As Tammy's faith helped her believe that those who die will join God, Tammy was not worried about those who already left; however, Tammy worried about those who are left behind.

The topic of belonging, which came earlier in the conversation, now seemed to connect with Tammy's death concerns. When Tammy said that the sense of belonging was important to her, it spoke to the extent to which she valued the connection with her family – her parents, brother, and son. Through the multiple deaths she has endured, she witnessed the extent to which the survivors struggled through the deaths of their loved ones. She was concerned about the connection between those who were left behind, those who supported each other through the sadness. For Tammy, the sense of belonging was crucial to her as she and her family members maintained their community. For those who passed, she believed that they were with God and hence she did not feel sad for them. She certainly had no fear or sadness about her departure either.

**Death-acceptance and Intimate Relationships.** The two relationships that were prominent in the first interview were also discussed in the second: the relationship with her parents, and the relationship with her son, Kyle. When I asked who the most important people were in her life, Tammy said it could be broken down in to two phases: before she became a parent, her parents were the most important people in her life. However, once her son was born, her son became the most important. Given that I wanted to focus on the present, I asked her to talk about her relationship with Kyle. Tammy spoke of the very first time she held him in her hands:

*I remember all through the pregnancy thinking oh this is the easy part. You know, it's the next 18 years after he's born and I was afraid that I was going to break this baby. Which didn't make sense because I was the oldest of six and I had taken care of younger siblings but I was afraid. But as soon as the baby was put in my arms it was like everything became automatic for me. It was, it's like I told somebody, I said my love for this baby is like breathing. It's just that natural of a part for me. It's not something I have to think about, it's not something I have to work at. It just is.*

Before Kyle was born, Tammy seemed to be concerned with planful, logistical aspects of her maternal role. However, such an aspect seemed to matter less as she first embraced her son in an embodied way, as she said *"It's not something I have to think about, it's not something I have to work at. It just is."* Tammy's love for her son emerged in an organic way, from the embodied interaction, rather than the conceptual thought of how she hoped not to "break" the baby. The first memories of



Tammy's most important relationship were characterized by the sensation of having her son in her hands. The fact that Tammy can speak to the embodied interaction speaks to how much embodied interactions are in the present.

Although Tammy valued the relationship, she was careful that she would not enmesh herself with her son. Tammy talked about her beliefs as a mother in the following:

*And so an important thing for me as a mother was to make sure that Kyle would be himself. I didn't want to try and be one of those parents that try to make the child into a copy of themselves or to live through the child or have him achieve things that I wasn't able to. I certainly hoped that he would be able to achieve things but I wanted it to be his achievements. And the most important thing for me was that he be himself and that he like who he was. And I thought if he is comfortable with himself, that's going to be the most important thing for him making his way in the world. So that's what I saw my role as a mom, was helping him become himself.*

Tammy made it clear that, although Kyle is a significant part of Tammy's life, she had no intentions of living vicariously through Kyle. In having an intimate relationship with her son, it was necessary for her to cherish his individuality. Tammy recognized the importance that her son will not fit neatly into her idea of who he should be. Leitner has said (1995) that the person needs to accept that the other person will not fit neatly in to his or her own construct system in ROLE relationships. As Tammy narrated the early years of Kyle, she expressed that she well enacted her belief of raising Kyle to be an independent son:

*As he got older, and was able to understand more things and able- one of the good things that my mother did do with us was she raised, she said I'm raising you to be independent. You know, you aren't going to be able to- I'm not going to be there for you all the time. And so as he became older, was able to do more for himself, I would let him do more and let him have more say in a lot of the decisions that went on. Not that I stopped being the mom.*

Tammy recalled her mother's saying that the purpose of valuing a child's independence was because the mother is not going to be with the child forever. As Tammy followed her mother's principle, she seemed to wish for her son to recognize that he needs to be able to live by himself, while recognizing that Tammy is still connected to him as his mother (“*Not that I stopped being a mom.*”) Tammy seemed to wish for self-other permanence, a developmental milestone in EPCP whereby the person realizes that the relationship still exists when one person is apart from another. As she said that she did not stop being the mother, Tammy seemed convey to Kyle that he needed to understand that the relationship would still be there even without holding her hand. The fact that she recognized self-other permanence indicated that Tammy and Kyle were starting to develop a ROLE relationship. Furthermore, Tammy's wish for Kyle to be independent may hint at her feelings for him when she passes away. As she said “I'm not going to be here for you all the time”, Tammy may be expressing her wish that Kyle can still be his own person even after she passes away.

As Kyle became more aware, Tammy decided to share more about herself to him:

*Also as he was older and able to understand more, he would get a little bit more information from me on what had gone on in the relationship. As he started to experience things with his dad, I could say, you know this is what my experience was with your father to sort of help him negotiate that relationship.*

Tammy became more specific about Kyle's relationship with his father:

*We had a difficult year in middle school when he was 13 and you know that's a big transitional time. And I've heard a lot of parents have told me that it was like somebody stole my kid when he was 13 and substituted some ogre or somebody took away my child's sense of humor. And then once we got past that age then everything came out ok. But he had some issues with his*

*dad and they involved that need for independence that kids go through in those teen years that his dad wasn't- and that was an issue in our relationship was that he just wanted to hang on too tightly and not give somebody significant in his life very much freedom or independence and so as Kyle was struggling with that with his father, I was able to share my experiences.*

Tammy shared above that Kyle's transitional stage led others to say that he has "lost a sense of humor." Although others noticed a change in Kyle and Tammy recognized that Kyle was going through a difficult time, Tammy's response to Kyle's change sounded accepting. In addition to self-other permanence, another important developmental milestone in EPCP is self-other constancy – the recognition that the other person is still the same person although he or she may become different. Tammy's relationship with Kyle seemed to withstand the changes that he was going through, strengthening the relationship further. Tammy showed that she is supportive of Kyle, despite the transition that he was going through; one of the ways in which she showed support was by opening up to him about her own relationship with Kyle's father. Before her brother's death, in which death became a personal event, Tammy's relationship with Kyle was already a significant one.

Tammy talked more about Kyle's growth – as he became older, he started wanting to spend less time with his father. In response to a father who struggled to give Kyle independence, Tammy helped Kyle to be open about his feelings toward his father. In concrete terms, this meant that Kyle worked on changing the visitation situations. The court eventually allowed Kyle to decide how frequently he wanted to see his parents, to which he decided not to see his father any more.

I asked Tammy how her relationship with Kyle was at the time:

*We've always been very close. We always talked a lot and it was, and I think the relationship with me was pretty much- I'm going to sound really conceited. I think it was a constant for him and it was, I'm hoping he found it supportive.*

Above Tammy expressed somewhat hesitantly that she saw herself as a secure figure when Kyle was going through a tumultuous time. She recognized the importance of having a "constant" figure when your life is otherwise unstable. Knowing the hardship he was going through, Tammy wanted to support him by providing him the stability that was otherwise absent in Kyle's life.

However, there were occasions in which Tammy expressed frustration about Kyle:

**T:** *He was not, during that time he didn't like to be hugged and touched and stuff.*

**A:** *From you.*

**T:** *From, yeah. And it was also some of the girls at school would tease him about not liking to be hugged. And that was difficult for me that I knew that where that was coming from was he couldn't say no to his dad but he could say no to me and know that it wouldn't affect my affection for him. So it was sort of a control thing. And when my brother died, that's when he started being more open to, I said you're going to have to put up with me hugging you from time to time and he had no problem with that. I mean, he was very open with that.*

The above statement reflected Tammy's needs that were previously unaddressed in her relationship with Kyle. Tammy also indicated comparing herself with his father; while Kyle would hesitate to accept Tammy's physical affection, he could not refuse his father's advance. However, upon experiencing her brother's death, Tammy decided to express her need for physical affection. I learned earlier that her brother's death made death distressing to Tammy – that she did not want to leave her loved ones. The feeling of loss and her thoughts about her loved ones brought Tammy to express her affection to Kyle. As Kyle returned Tammy's need for physical affection, their relationship became more reciprocal and thereby more intimate. I asked her to elaborate on the day that her brother passed away:

**T:** *I was just recalling the day and Kyle had not been open to hugging for awhile and he knew that that was what I was going to need and he hugged me. And he let me hang onto his arm at*

*the funeral and that was a turning point in his ability to start expressing physical affection with me again. Beginning as a comforting thing and then gradually it developed to the point where just the affection between us- I can hug him and he still doesn't initiate but he'll see me reach out and he'll reach out and hug me and pat me on the back and the whole thing.*

*A: What did it mean to you?*

*T: Well there was a combination of just the physical comfort for the pain that I was feeling. And the realization that Kyle was opening up emotionally.*

The fact that Tammy used the word "physical" indicated that the body did matter. I was also struck by the fact that Tammy said that it was a turning point at which he started expressing physical affection with her *again*. While I do not know exactly how long she had been missing his affection, I did recall the very beginning of our second interview: the very first time that Tammy had Kyle in her hands upon his birth. The impact of holding him in her arms sounded like a powerful moment in her life; the theme of physical expression of affection was returned in the moment when Kyle reciprocated Tammy's need for physical intimacy.

The physical re-engagement between Tammy and Kyle had significance beyond the fact that Kyle was able to express himself to Tammy:

*A: so when you and Kyle hugged it also sounded like Kyle must have been sad but also he was caring about your sadness.*

*T: Exactly. And it was both knowing that he was able to feel sadness and knowing that he was able to care about me and to feel empathy with my sadness. That was very important for me.*

As Tammy showed the ways in which she empathized with Kyle, he was also able to receive Tammy's feelings. The hug on the day of the funeral represented the point at which the empathy between Tammy and Kyle became reciprocal. Leitner (1985) stated explicitly that true intimacy involves reciprocity. As a result of death becoming a more personal event for Tammy, their ROLE relationship became even more intimate. Finally, I asked Tammy whether there was any legacy she wanted to leave behind after her passing:

*Gee, I haven't really thought too much in terms of legacy. I hope that he'll always, I think he's always known that he was loved and I hope that he never forgets that he was loved. That is one thing that I have gotten from my family is I have always known that I have been loved unconditionally. They might not understand me, they might not agree with my choices, but by golly they love me and they'd be there for me no matter what. And I hope that that's how Kyle thinks of me and I've certainly tried to let him know that no matter what you do and no matter choices you make, I might not be happy with some of your choices but I will always love you. And I hope that he has felt that throughout his life and I hope that that will always be with him, that that will sustain him in the future.*

Tammy's response spoke to the level of intimacy in her ROLE relationship with Kyle. The legacy she wants to leave behind revealed not only a core principle of her family, but also the effort Tammy brought to convey unconditional positive regard towards Kyle. What role did intimate relationships play in Tammy's accepting of death? Tammy's love for Kyle was always a constant. The deaths in Tammy and Kyle's life seemed to deepen the nature of love between the mother and son. Furthermore, Tammy said she was never fearful of death. In one sense, she was always death-accepting. Rather than her own death, she was more concerned about how her death will affect others. She saw how her brother's unexpected death troubled her parents. She was most notably worried about her son. The relationship with her son deepened further, as she addressed her need for physical affection upon her brother's death. Hence, I found that Tammy's relationships with others were intimate enough, such that she was always accepting of her own death. Furthermore, I found that her ROLE relationship deepened when death became a personal event for her, through the death of her brother.

**Member Check.** I went back to Tammy's house after I had finished writing the analysis. Tammy requested to read the section on her own, so I sat at her kitchen while she read my analysis. She chuckled as she noticed philosophers and psychologists associated with her statements. I asked if I represented her views accurately, to which she affirmed that I did. She just thought it was funny that she did not even think of renowned philosophical and psychological theories when she was answering my questions. She also said that she was pleasantly surprised by how much she was making sense. She complimented me that I had done a good job with the analysis. She thought it was particularly insightful for me to notice the connection between the first time she held Kyle in her hands, and the time when she hugged him at the funeral. She had only one clarification to make about the analysis, which concerned her statement that she wants to live close to her son if he moves away. She only meant that she wants to live close enough to her son, so that he will be near when her body deteriorates. It was not the case that she wants to be close to him so that she can be attached to him at all times.

## **Ed**

**Ed's Story.** Ed is a 66 year-old Caucasian man who retired from his medical job two years ago. He currently lives with his wife. From the phone calls, it was difficult to get an impression of Ed. His voice quivered, and I could not estimate what kind of person Ed was. Perhaps the ambiguity made my first encounters with him a pleasant surprise. As I arrived at his place, Ed was very courteous. He invited me in kindly, and offered me a glass of water. He seemed very effortful in making his place the most comfortable for my interview. Although Ed was unexpressive with his face, I immediately got the sense that Ed was a kind-hearted man.

The room in which the interviews took place was a large living room that was not separate from the other rooms. In my first visit, I noticed that the living room was quite near to the other parts of the house; in particular, his wife was cleaning up from dinner in the kitchen right next to the living room. I thought about whether we would be distracted; in particular, I wondered whether the presence of his wife would influence Ed's responses. Upon having him sign the informed consent, I asked him if we could have the interviews in another place, in case Ed did not feel fully comfortable in the living room. Ed wondered for a short while, and eventually said that he did indeed feel comfortable, even with the possibility of his wife hearing the interview. I eventually agreed to conduct the interviews in the living room.

**Ed and Death.** Our first interview started as I asked him to describe his life in a general way. It was a conversation opener, but I was interested to see the first thing he would say. In response, he revealed a key piece of his life.

*I feel particularly lucky at this point right now. Uh- one of the things that you may or may not have realized is that I have Parkinson's Disease. And that is something that does change your life quality. And in my case, the- uh- physician diagnosed it early enough that they were able to get me on medication that tends to keep it stable. That- it won't- it won't stop it forever, but it will- it helps the situation. And I feel extremely lucky in that respect. The bad part- the- the downside is that I've had to give up my practice. Uh- I was a- I was a doctor. And I've had to give that up. And I sort of ha- had- had identity- my identity was tied in with my profession. And now that I'm not the doctor that's at the clinic that people are used to coming to, I'm- I'm not anybody. I'm not a- a- any particular person. And that's- that's hard to take.*

Ed revealed losing an essential part of himself – his profession as a doctor. In constructivist terms, essences of identity are called core constructs (Kelly, 1955). Honos-Webb and Leitner (2001) argued that losing one's core construct can cause great distress. Although he started his narrative with a positive “lucky” note, the opening quickly turned to a narrative of loss so grave that he is “*not anybody*.”

Ed considered himself fortunate for how things turned out. He was grateful for his physician

and the medication keeping him stable. He was also accepting about the fact that he could not continue as a doctor in his condition; however, his acceptance and gratitude did not alleviate the frustration he had about losing his core identity:

*It's particularly difficult in my profession because what I'm doing is giving shots and doing surgery and taking x-rays and doing fine-point kinds of activities- things that- um- you don't dare make a mistake because you won't either diagnose it correctly or you won't diagnose it at all and have to repeat the procedure or at least find another way to get the right answer. And that- it runs the bill up- uh- endlessly. It means that the patient is not going to get the best of care the first time around and may have to go around a second time to have that happen. And I didn't- I didn't want to do that to my clients. So I knew that I was going to eventually have to give up my practice. But I just can't come to terms with it.*

Ed seemed to be in a difficult spot where he struggled between recognizing the risks of the disease and dealing with the loss of his core identity. It seemed to be a part of his professional identity to be ethical about his practice. If he were to be a doctor with integrity, he could not do a disservice to his patients. However, what also came was the inevitable end of losing an identity that he valued so highly.

*What I don't know is- uh- what to expect in terms of time- (pause) in- in the det- the deterioration of the- uh- muscles that the dopamine- dopamine was taking care of. Um- if I had a magical- if I had a crystal ball that I could see forward, I would cast it probably what it will show is- uh- about every five to ten years there are changes that I can point to that will probably tell me that either I'm getting better or worse- one thing or another. And that- very likely there'll be some steps- uh- orthopedic- uh- devices that I'll need to get around the house. You- you ha- you haven't seen our house, so you don't know this- this, but all of the major doorways are double in size. Uh- be- because there- there may come a time when I get- when I stumble and fall, and my wife won't be able to lift me. And they'll need to get the emergency people in to get their- their carrier in.*

Throughout the interview, I was struck by Ed's particular way of responding to my questions. From his explanation of dopamine functions, his language was professional and precise. To me, his explanation gave me a sense of how much he missed his former identity. Furthermore, as his frustration continued, I realized that his own grief over his own identity turned into an interpersonal concern. First, although I had not seen the entirety of Ed's house, I did realize that the entrance of his living room was larger, which explained the fact that it was not that separate from the kitchen. Hence, Ed's own physical deterioration had implications for the very structure of the house in which he and his wife resided.

In asking Ed about his future, I attempted to bring the subject matter closer to death. In joining Ed's journey from his retirement to the rest of his life, I realized that his wife played a key role. Ed says the following about his wife's role in his future:

*I regret that my wife will have to make a decision about [preparing orthopedic devices] 'cause it- it's- it's not fair for somebody else to have to deal with the- the infirm individual. Uh- she married me for better or worse, and that's one of the worse parts of it. But- and she doesn't complain. But uh- there will- there will come a time when I'll have to make those decisions, and that'll- that'll- that'll be even rougher than it is right now.*

Ed foreshadowed the difficulty that awaits him in the future. Although Ed remarked that his wife does not complain, the weight of responsibility he is putting on his wife felt tangible. As Ed acknowledged that his wife is the appropriate person to take care of him, he expanded this to be one of the "worse" parts about her marriage with him.

As we talked more about the future, I finally asked him about his end of life. Again, Ed responded to me in precise language.

*What'll happen is I'll probably get pneumonia. Uh- unless there's something else that rears its ugly head in the meantime with me. But probably pneumonia. Mainly because the period as- as there's more and more deterioration results in a lack of swallowing mechanism keeping up. And as a result, you tend to get- uh- infections in the throat and eventually, into the lungs. And you die...I- I've often thought that it would be much more- uh- much better outcome to simply- um- drive- drive the car off the highway into a tree and just let the families sort out the details. But- uh- I've never thought about it to the extent of- uh- anything more than just wondering.*

The use of medical terms, as well as his second-person narrative ("you tend to get...") gave me an idea of what he might have been like when he was still practicing medicine. I wondered whether Ed's speech was reflective of his grieving for his identity as a medical professional. The mechanistic analysis changed to have an emotional component in the end, as Ed revealed that he wondered about driving off of a highway. Ed implied that there is something bothersome in the future he foresees for himself.

Although Ed said that thoughts of ending his life do not go beyond the level of wondering, I was still curious as to how he felt about dying. As Ed did say that he thought about it often, his attitude towards death called for more questioning:

*I don't get a pit in my stomach when I think about death. I don't- um- (pause) I- (pause) I- I have- I have done a little bit of looking about the specifics of how- how we die. Uh- which has helped me understand what kinds of things I- I couldn't do if I decided I wanted to do- something like that. One of the difficulties with planning- planning your death is that when you get it planned, you're too late to do anything about it. You can't- uh- accomplish the process yourself. And I- I be- I would then- then think about something like Dr. Karvorkian and his- his work. Um- and- then- then it would begin to seem silly to me, so I wouldn't think about it anymore. (pause) But um- I- I- I don't- I don't feel that it- that my death must be a suicide. But I surely don't want to have to foist on my wife and family the- the care that goes with deteriorating- the conditions.*

As Ed said before, he has given much thought to the dying process. As Ed repeatedly dismissed the idea of committing suicide, I realized that he was not determined to end his life. Ed gave the impression that he was carefully thinking about his dying process, which will have impact on himself as well as others. As he learned that "when you get it planned, you're too late to do anything about it" he seemed to be bothered by the lack of control he had of his fate.

In the latter half of his response, Ed showed his struggle in his anticipation of death. Although he has yet to determine his death as a suicide, he also expressed that he does not want to be a burden on his family by making them the caretakers. Ed seemed to be in a position in which he accepted death as an inevitable end, but has not yet found the way to avoid being a burden on the people who are closest to him. As Ed mentioned his wife and family in the end, a significant factor to his struggle seemed to be his relationship with his family. I asked him to elaborate:

*I really very strongly feel that if anything struck me as being done specifically because the family had to make a major change due to my health, I would then immediately begin to think more seriously about it. Um- I- I- it- it wasn't their fault I got sick. It is a- it was a- it's a disease that- uh- proceeds slowly enough that I can make changes in my life quality and my lifestyle before it happens to me. Uh- before hand- before it's handed to me. And since I have those options- I- uh- I- I just- I don't know that I could stand getting up in the morning and realizing that I had to- every single morning- had to spend an extra hour getting ready because I- I couldn't do it myself. And my wife had to help with that, and that extended her day. And just made it difficult for everybody.*

Ed's response confirmed that his wife and family are a major component in his struggle. In

other words, his planning for death involved planning not to be burdensome to other people. He also made a claim above that, because the speed of his disease still allows him to make his own decisions, he has the responsibility not to let the disease affect others so much. Ed thought that he needed to do all that he can so that he will not be a burden to his family. He even claimed that he would become more serious about death-planning if his family needed to spend more time on him than themselves. Such thoughts made me realize that his wife and family are the core of Ed's struggle in planning for his death. The disease cost Ed his occupation, and Ed did not want to let it prolong the extent that it would cost the lives of his loved ones as well. Interestingly, Ed did not think of his wife's helping him as a gift to him; rather, he seemed to hesitate being dependent on his wife.

As I explored more about Ed's attitudes towards his own death, I wanted to see if he has always taken such attitude:

*I don't think I really thought about what death would be like until I got to the point where I was curious about how I die- how I would die.*

It became clear that death was not a salient topic in Ed's life until he was diagnosed with the Parkinson's. Ever since he had to deal with the loss of his core self-construct as a medical professional, he realized that he needed to plan for death. The planning seemed especially necessary, given that he realized the weight of the burden his loved ones will have to endure if he does not prepare for it soon enough. I realized I did not have a clear idea of what he meant by planning for death, so I asked him:

*A: What do you exactly mean by planning death?*

*E: Making sure that- (pause) making sure that- (pause) let's see- how would I- how would I state it. (pause) Making sure if I could that it wasn't painful- that it was quick and immediate. That it resulted in- uh- no pain because of it's being instantaneous. And somehow, making sure that the lawyers and the insurance people don't have- don't make it rough for [my wife] to get what's due her from the various policies and so forth.*

Ed did not say suicide; however, he again emphasized that it should not be a burden to him or others. As Ed and I reached the end of the first interview, I realized that there was one crucial question that I have yet to ask. What does death mean to Ed? The beliefs he had about what happens upon death seemed important in interpreting his plan for the end of his life. Ed answered with the following:

*Death to me...is the cessation of life quality, which happens to include a conscious appear- a conscious ability to either enjoy or not enjoy life. To- um- to be able to qua- quantitatively list what kinds of things- uh- constitute that quality of life. And when those things cease to be enjoyed and when there's no further enjoyment participated and when the- the- when the present state of affairs is such that- the- the quality of life has no- has no meaning at all, then- then the body is- is done. I don't- I don't feel that I'm- I'm going to ride- walk up on a sunny hillside and meet Jesus or anything like that- I don't- that doesn't- that isn't a part of my makeup.*

Ed made it clear that he was not expecting an afterlife. Furthermore, I was struck by the emphasis of "enjoyment" in Ed's definition of death: the person dies when he or she ceases to enjoy life. It was not a biological or mechanistic cessation that determined someone's death, it was his or her "conscious ability" to enjoy life. Ed's definition seemed fitting to me. For Ed, who valued the relationship with his wife and family, his conscious awareness seemed necessary in enjoying their company.

**Death-Acceptance and Intimate Relationships.** From the first interview, I already had an idea of whom Ed would bring up in the second interview. His wife was the main person he thought about as he planned for the end of his life; hence, it did not surprise me when Ed said that his relationship with his wife was the most important. Ed told me that he met his wife through the church choir he participated in while attending medical school. The year was 1971. Upon meeting her for the first time,

Ed remarked how cheerful, smart and active he found her. It was very easy for Ed to approach her. Ed said more, as I asked him what the beginning of the relationship was like with his wife:

*It was- at that- that age and stage in- in American youth, you usually spent- (coughs) spent some- some time just simply thrusting and parrying and uh- um- throwing out questions and seeing how the other person answers them. And finding out that you both like chocolate shakes or you both like mocha shakes or neither of you like mocha shakes or- you know- the little things like that that kind of form the boundaries- the- the nebulous boundaries that- within which that person resides. And um- and I had a similar take on my various personal quirks and so forth. And um- then you- you quickly learn that there are some places where these- these figures cross paths and that there's a common bond there of one sort or another. And then it goes- goes from there. I knew- I knew from the time I had decided that I was going to date her and see what it was going to be like- that she was probably going to be the one that I ended up with.*

As he discussed the beginning of his relationship with his wife, he seemed to describe the very process in which any person navigates in the beginning of the relationship: sharing oneself to another person to see how much each person has in common, and to determine the boundaries between the two. With his wife, in particular, Ed seemed to sense that this relationship was indeed going to be special, as he already sensed the one he will “end up” with. Even though Ed already saw a future with his wife, I presumed that his relationship did not stay the same. I asked him how his relationships have changed over the years:

*It has- it has changed. I would suggest that she has a much stronger role in- uh- planning of things that I thought I had as my providence when we got married. Um- none- not no one particular thing. But several things- uh- budgeting and- uh- whether to make large purchases- um- you know- re- refrigerator- or freezer, stove- things like that. The- those bigger- bigger items I- I- I thought that I was making most of the decision. But as it turned out in hindsight, probably she had as much of a role as- as I did. It was pretty equal. Um- (pause) let's see- she- uh- (pause) she- she had a habit of- if she was going on a- a- shopping jaunt- or similar type activity, she would also extend that to include some interesting looking store that she hadn't planned to be the- taking- take time for. And we'd come home with something really unique.*

In the statement above, I see that his wife did not come to have a stronger role in the couple's decision-making. Rather, it was that Ed's view on her contribution had changed over the years. As Ed reflected in this passage, he realized that his wife's role in making decisions – such as buying a refrigerator or a stove – was much bigger than he originally thought. Although Ed acknowledged in the first interview that his wife was an important person in his dying process, he seemed to be even more aware of the value of his wife in the second interview. In evaluating his constructs, Ed was becoming more aware of his wife's influence onto him. Ed illustrated this case with the following story:

*One time she went to an auction, and in- in Vermont, the auctions continue year-round. And even when there's snow on the ground, you go to the auctions. And this one farm auction that she went to, she bought a box of books just 'cause they were just selling them for a dollar. And the box was huge. It was like this table here. And it it turned out at the bottom of that box was a 1731 medical text, which is invaluable to me. It might not be to others, but it certainly is to me. And I still have it and been trying to keep it in good shape. But that's the kind of thing- if she hadn't decided to stop at that auction and buy a- and buy a whole box of books for a dollar, then we wouldn't have had those items. And so I- I got to the point where in general, I- I defer to her judgment on those items 'cause she's usually right when it comes to value and style. I'm not the author that- that she does that.*

The story above exemplified the change within Ed, as he consciously started to defer making



decisions to his wife. Ed recalled a serendipitous moment when his wife's seemingly whimsical move led to uncovering an object that Ed continued to value for decades. By becoming closer to his wife, he was finding that her actions ended up affirming his values. As a result, he gave more trust to his wife in making decisions. In contrast to the very beginning of their relationship in which they were both forming their “nebulous boundaries,” Ed and his wife were deepening their relationship. The relationship between Ed and his wife was also significant because Ed felt comfortable letting his wife make decisions, when he used to think of himself as the sole decision maker. In other words, he was comfortable with changing his core constructs in the relationship with his wife. Ed said the following:

**Ed (E):** *I feel extremely fortunate that I- that I've been able to have a wife that I can trust- uh- for- for any number of reasons. Probably the main reason being that my ego doesn't suffer as much if I know that I have trusted in her that I need to get things done. So...*

**A:** *Could you break down that sentence for me- your ego doesn't suffer as much with that trust?*

**E:** *I have a fairly strong ego. But I have also- have a- it's kind of a- well, I guess you would say less of a strong- personal strength- uh- personal sense of duty and so forth. And so I'm- I'm more willing to knowing that she is going to do a better job, talk to her, get a better idea about who's going to do it and then let her do it. Because she- she just get it done better than I will.*

As Ed openly acknowledged that he has a strong ego, he made a connection between the trust that he has upon his wife and his own self. If he were to have a strong ego, that would conflict with his wife owning responsibility in making decisions. However, given the trust that was built upon various affirmations in the relationship, two conflicting elements – his strong ego and his wife's willingness to make decisions – reconciled.

When Ed's relationship with his wife was characterized by trust, my next question was how Ed's confrontation with death affected the relationship. Given that Ed said in the first interview that he did not think about death until he was diagnosed with Parkinson's, I asked him how the diagnosis affected the relationship:

*I had so said it in my mind that I was not going to be dependent on others. That for a long time, I rejected her attempts to help me adopt a life quality that I should have adopted a long time before that. She knew that I was going to be needing special furniture and special equipment, special ways for eating and so forth- some of which I've already adopted. But some of them I haven't gotten around to yet...her attitude was let's be proactive, let's get going with what we need to do to help you. And she would scour magazines and go to flea markets and stores where they might have things that were equipment that could be used. For a long time while I was getting accustomed to the disease, I had trouble getting myself fed and getting my daily washing my face and things like that getting that done...But she was way ahead of me on all those things. And she wanted to have me try a variety of occupational therapy kinds of things, which I didn't want to try and haven't yet. But she didn't press the issue. She said, “OK. If that's the way you want to have it, that's the way we'll have it.” And so she maintained her ideals- her standards and waited for me to catch up, which is what happened. I eventually caught up and was able to dress myself and other things. So...I think that sums it up pretty well. And that's one of those things that I look back now, and I say to myself, “Thank God I was introduced to her. And thank God- I thank God I married her. And thank God we have a marriage that has- has lasted all these years and still seems strong.”*

From the above statement, I was reminded of the “strong ego” expressed earlier. Perhaps it was not the strong ego per se, but it was the initial dismissal of his wife's caretaking showed that a refusal to be dependent on others. His wife sought to care for him, but nevertheless gave him the space to reach his own conclusion. His wife's attempt to let him grow in his own way showed they always saw that separateness was a key component in true intimacy, again, as Leitner stated (1995). In the end of his

response, Ed's expression of gratitude showed a culmination of his appreciation. Not only were they able to build a ROLE relationship characterized with trust, but they were also able to sustain it all these years; even when the most testing of times came upon Ed, his wife was still able to show care and support his independence, thereby allowing him to grow in the final stage of his life. Ed also respected the separateness for his wife in turn:

*I feel very strongly that I don't want her to have to make changes in her ca- professional curriculum in her teaching load, in her religious habits, and her- um- her- her ideals of fun- uh- picnics, parties, whatever. I don't want her to have to change that because of me.*

While Ed admitted that he did need to depend on his wife for his ailment, he acknowledged that it should not be done at the expense of his wife's life. Ed's opinion was reminiscent of Hardwig's (2004) argument that the dying have the responsibility to think about those who will be left behind; before devaluing death and prolonging life, the dying have the responsibility to think about how they may affect their survivors.

Ed and I were nearing the end of the interview, and we discussed how he would like his wife to remember him after he passed away. He gave me one word: *congeniality*. He said that he was at a discussion group in a conference, and was asked to come up with a term that described himself. He thought of the word that meant to him “*interaction without stress*” or “*resolution to an argument or something very upsetting*.” He said it described his philosophy well. Furthermore, when he told his wife that he put down the word at the discussion group, his wife commented that the word describes Ed well. Hence, the word not only captured Ed as perceived by Ed, but also Ed as perceived by his wife. My last question to Ed was what his wife meant to him, to which he said the following:

*I think it probably has to do with congeniality. Um- she is- she is a barrier between me- my personality and the world because she can handle the situations that I have trouble with. She- she can handle the tiffs and the neighborhood relations and the- she can stand up at a meeting and talk to somebody and argue with them. And uh- in the public eye, and I would no more do that than kiss a pig. (laughs) But um- my- my- my bent toward congeniality would- would prevent me from doing something like that because it would- it would mean that I might get somebody who would have a strong re- response, and I would- I would be out of luck. I wouldn't know how to argue with them. So I would have to sit down and take the shame of having thought I was going to- but- do a solution and not do it. Um- congeniality has to do with keeping the family relations good, and- and she does. She's sort of the center of the family's activities. Um- (pause) I- I'd say my wife is my- (pause) my bucket full of congeniality.*

His wife seemed to play a key role in his life. Although he still struggled in accepting his wife's help, it was clear that he was unable to define himself without making reference to his wife's work. After all, she was the person who mediated the relationship between Ed and the world. In order to keep his philosophy of congeniality, it became necessary for him to rely on his wife and sustain the familial relationship. In the end, he used the word with which he defined himself to define his wife: a bucket full of congeniality.

In sum, as Ed deepened his relationship with his wife, he was more able to accept his mortality. At first, his diagnosis of Parkinson's made him despondent to a great extent. He was distraught over the fact that he lost his core identity as a medical professional. However, as he dealt with his ailment, his appreciation for his wife grew stronger than before. The more he reflected on his past, he seemed to find out more about his wife's contribution to his life. He seemed to become more aware of the fact that he cannot live without her, to the point that he is not able to define himself without thinking about what his wife means to him. As he realized the ways in which his wife played a key role in his life, he became more accepting towards death. He now struggles to find ways in which his death would not be burdensome to himself and others, most notably his wife.

**Member Check.** I visited Ed back at his house to show him what I had written for his analysis. Ed suggested that I read my analysis out loud to him. As I read, Ed listened intently, and nodded as I looked up to his face. He would stop me from time to time to make comments about what he thought. For example, he found it intriguing that I thought his language was reminiscent of his old profession; he did not think that I represented him inaccurately; it was just something that he had not thought about before. Furthermore, he was surprised to find that “enjoyment” was a key factor in his definition of death. He told me that he did not consider himself to be the kind of person who cares about enjoyment. Overall, Ed told me that my portrayal was accurate to his experience, and told me that he found his participation meaningful.

## **Quinn**

**Quinn's Story.** Quinn is an 86 year old woman who resided at a Nursing Center in Southwest Ohio. She had been living in the nursing home for the past 15 years. I was unable to get in touch with her at first, as she was in the hospital for three days around the time I was recruiting participants. The director of the Nursing Center even told me that I may not be able to interview her, given that she was in critical condition. However, Quinn eventually came out of the hospital in an improved condition; she agreed to see me for the interview. When I met her for the first time, she seemed alert, and did not give the impression that she recently struggled between life and death.

The first thing I remember about Quinn was the handshake. As I shook her hand, she mentioned that my hand was warm. In contrast, I noticed that her hand was very cold. Before I said anything, she said that she had a “cold hand, but a warm heart.” She later told me that it was just one old saying that people used to say. Her comment put me at ease. I already started to trust that she was comfortable with my presence.

Quinn was clear-headed; as I signed the informed consent, we decided on the date for the first interview. I asked whether she would like me to write down the date somewhere, so she could remember. Quinn told me it was not necessary. She remembered the dates and times of all of our interviews. In fact, she chuckled at me for the one time I was five minutes late.

**Quinn and Death.** Quinn seemed to be at ease as she talked about her attitudes towards death. Throughout the two interviews, she barely changed her tone of voice. She was either nonchalant, or chuckling about a funny thing that once happened. She was ready to talk about death even before the first interview; as I talked about my experience with my grandfather, she started talking about her father's death that she never got to witness. As death entered the conversation from the very beginning, it was easy for me to ask her directly what she thought about her own death.

*A: Do you think about dying?*

*Quinn (Q): Yeah, every once in a while I wonder why I'm still here since I'm eighty-five year-eighty-six years old. And I thought well, it's about time for me to go.*

Quinn responded in a very comfortable manner. I was intrigued by Quinn's nonchalant response to my question. It sounded as a very passive way of anticipating death, which was reminiscent of Kubler-Ross's (1969) “acceptance” stage. She was not only unafraid of death, but she was also waiting for it as a necessary event. Furthermore, as she questioned her status of being “here” she suggested that her being alive was the abnormality, and that she should be “going” or she should have been “gone” soon.

She later told me that each morning she wakes up and is surprised that she is still here. Quinn's expression of being “here” and “going” soon became contextualized in her Christian faith, as she said: “Yeah, I think it's about time. I'm wondering why the good Lord doesn't call me.” She sounded like death was neither a good event nor a bad one; she was simply waiting for death to arrive. However, once she said that death was God's calling, it was no longer a simple wait for death. Death indicated a relational event between Quinn and God. It was God's decision that she was alive, and God was

keeping her alive for a reason. However, when Quinn answered my question about death, I could not get a feel for what being alive meant to her.

So I asked Quinn on what it means to her that God is still keeping her alive.

*It means the good Lord isn't ready for me yet. One time I kept wondering why I wasn't dying, and all of a sudden, and my mind or something said, "This is your guardian angel, and God isn't ready for you yet."*

From her response, it seemed clear that God was communicating with her through a messenger. The fact that she was alive was not dependent on any theory; it was rooted in the personal experience of communicating with God and having a relationship with Him. Hence, in our conversation, Quinn seemed to treat death quite as a natural event. The line between life and death was not a dramatic unworldly distinction. When God feels ready for her to die, then she simply leaves for heaven.

*I have to just wait until He's ready. And one time- uh- after I come back from the hospital, I felt like I was just floating around in the air. And it wasn't long after which they tried to push something back in me. And I woke up.*

I recalled the director of the Nursing Center telling me that Quinn was in the hospital and she was not sure whether Quinn was going to be alive for the interview. At the time, I knew that it was uncertain whether she would live through her hospitalization. What I did not know was that Quinn would have accepted either outcome. Furthermore, Quinn stated that she had floated around in the air as she wandered between life and death. As Quinn reported her experience as a simple matter of fact, I almost felt out of place for being surprised about her out-of-body experience. For her, whatever was happening at this moment was nothing to be surprised about. Of course, I was intrigued by an experience that sounded quite foreign to me. In the interaction below, I ask the question with curiosity and bewilderment that I could not hide.

*A: Okay. How- how- what do you make of that?*

*Q: I don't know what to make of it...It gave me the idea that dying i- isn't hard to do. Some people they find it so hard when they're sick, and they can't die.*

The interaction felt awkward at best; I nervously asked Quinn for her interpretation, to which she refused to elaborate: on the one hand, I was intrigued and fascinated by Quinn's experience. On the other hand, Quinn seemed uninterested about her own experience. I realized that her disinterest was symbolic of her attitudes towards death: it was nothing to be scared of, and nothing to find difficult. In constructivist terms, her construct of death seemed fit neatly into her already established construct system. Kelly (1955) stated that, for most people, death is one of the ultimate threats life can present. For Quinn, however, integrating the death into her construct system brought no threat or anxiety.

Although it was clear that Quinn was not fearful of death, I asked if she had always had this attitude. In response, Quinn told me that she only recently started thinking about death. She did not specify any triggering event that made her think of death; she only told me that once she turned 86, she expected death to happen soon. As death became closer to her, I wondered whether there was anything she does differently. The only change she indicated was that she prays to her rosary more frequently. She stated that going to heaven is important and said that "*You don't want to go to the other place. It's p- it's a place of suffering.*" I noticed that Quinn's attitude towards death had to do with her ideas of what she thinks happens when she dies. As I asked her directly, Quinn gave me her usual concise and straight-to-the-point response:

*Q: I hope to go to Heaven. I'm trying hard get ready for Heaven.*

*A: How exactly do you mean- getting ready?*

*Q: I pray the Rosary everyday and say my night prayers. And- and make sure I talk to Jesus a little bit in the evening.*

I asked what kind of place she imagined heaven to be, to which she only said that it was a wonderful place you will be until the end of time. It did not sound to me like she was interested in why or how it was wonderful, but only that it was a place that she was meant to go; the specifics hardly mattered. The discussion of the benefits of going to heaven did not seem to be valid questions for Quinn. What mattered was that she goes to heaven, and that she worked hard to go for it. In doing so, Quinn also told me that she needed to commit to “*being good, and taking care of yourself and others.*”

I asked her how she is doing in terms of being good and taking care of herself and others.

*A: Do you think you do well in that respect?*

*Q: Oh yeah because I- at church I serve as a Eucharistic minister. And when I came to the retirement home, I used to take the Eucharist to the people in the rooms that couldn't get out. And that was a big experience. I had a hundred year old lady, and she said she wasn't worthy to receive communion. And I said, "How about if I prayed the Euchar- uh- Act of Contrition with you?" And she said, "Not even that'd help." I kept wondering what a lady a hundred years old would've done.*

As she described her past chores of taking the Eucharist to others, she illustrated that her daily behaviors had ties to her attitudes towards death. Whether or not she was conscious of it, the act of taking the Eucharist to people was meaningful in that it fit the idea of her being good and taking care of others. The idea of being good meant that she was going to heaven, a place she imagined she will enjoy. In such a way, Quinn's daily actions brought integrity to her construct system: her ideas of mortality were connected to her ideas of death. I later learned that her “being good and taking care of others” extended far more than taking the Eucharist to others in the retirement home. She told me that she devoted much of her life to taking care of her ailing parents. She told me about the events that led her to retire:

*I retired and stayed home with my mother. At first I could go out and do things for myself and not worry about her. But later she went blind, and I couldn't leave her alone. So I had to get my brother or sister to come stay with her while I- if I wanted to go out.*

She also spoke of her father:

*I helped with my father when he was sick and he got pain and had to go to the hospital. I took him to the hospital. And took my mother there and afterward, I come back and got her. And went home. (pause) And I used to stop and see my father every night when I went home from work- when he was in the hospital.*

As Quinn talked about her efforts to be with her family, she spoke in her usual nonchalant voice, which did not convey a sense of complaint. She stated it simply as a matter of fact. From her past history of helping others, I realized that she was always engaged in actions that had implications towards her understanding of where she will be when she dies. Given that she already engaged in activities that enabled her to go to heaven, it did not startle her when death became a personal issue. Throughout her life, she had been building her construct system in a way that could integrate death without friction.

**Death-acceptance and Intimate Relationships.** Much as the first interview, Quinn did not change her affect during the second interview. She talked about her relationships in a casual manner. It was difficult for me, at first, as I was operating under the assumption that there was one relationship that she could identify. Although I was not sure how to proceed with the interview, I soon learned that, for her, the relationship was not just one person, but her entire family, which included her parents and six other siblings. Quinn talked about her family:

*The most important is family. My uh- one brother- he didn't want me to be without yarn, so he gave me fifty dollars to buy some yarn. (laughs) Yeah. That was nice. And my youngest brother- he helped me pick out the- the yarn. And the- and he got me this blouse- and this shirt that went*

*with it. Slacks that went with it. And that took the fifty dollars.*

Quinn first described her relationships with a couple of her siblings. She said that she felt especially close with her older brother. Although she was not initially close to the youngest brother, as he was 17 years younger than her, she said that he now is the most important person in her life, given that he takes care of her finances.

She said that she tried to keep in touch with her family even after she started working on her own. Although the ways in which she talked about her family members were always concrete, it was clear that her life revolved around her family. It would have been impossible for Quinn to tell her own story had it not been for the relationships with her family.

Quinn confirmed:

*Well, we were always very close. And uh, we had uh- we had the whole family at the table for every meal. Not like they have today- the one goes this way and one goes that way. They- everybody was at the table when it was time to eat. (pause) Uh-huh. And we used to play games together. And we lived a- on a farm where the neighbors weren't that close. So it was mostly the family that stayed together.*

In the comparison between current trends and the past, she emphasized how important it was that she was with her family all the time. Furthermore, as she reported that she was physically distant from her neighbors, she indicated that most of her socializing occurred within her family. From her report, entertainment and eating were essential family activities that connected her and her family together for many years. Quinn eventually left her home to work in Cincinnati, but moving out of her house did not separate her from her parents. She said that she still went home to play card games with her family. She reported her parents reassured her that the relationship was intact no matter where she was.

*And mom said to me- once I was upset about something- she said, "You always got a home here with us." They make me sure that I didn't have to worry about where I was going to live.*

From the line above, I saw that her mother responded to Quinn's feeling upset by assuring her that she always had a home. Quinn, hence, always stayed close with their family. Quinn eventually moved back to her old house and community. Even after she had retired, she took care of her ailing mother until her mother passed away.

Listening to Quinn, it was evident that Quinn's relationship with her family had been a constant in her life; it was a secure relationship that had always been in Quinn's life. From a constructivist perspective, it seemed as though her relationship with her family had been a core value in her construct system. Her family defined her life. To her, being close to her family was unquestionable. The fact that I was asking more about her relationship with her family may have been unfamiliar to Quinn:

*A: So your family's still close to you even after you moving out.*

*Q: Mmhmm.*

*A:...How do you feel about that?*

*Q:...Well, it- it's just naturally I think. Naturally you feel close to your family. Or is that something I just feel?*

It seemed as though Quinn was not used to my line of questioning. The interaction above represented the overall tone of our conversation in which Quinn seemed confused about the very fact that I was asking her questions about the family. Her relationship with her family is simply described as "close," and that was the most she could say about them.

As her relationship with her family was a constant for her, I wondered whether her awareness of death affected her relationship with her family. It was evident from the first interview that her thoughts about death did not arouse any fear for Quinn. Given the lack of fear, I realized it was questionable whether thoughts about death affected her interactions with her family. As expected, Quinn did not

indicate any change in her interactions with her family. Furthermore, Quinn did not change her nonchalant but jovial way of talking.

*Q: Mmhhh. My- my brother and I went and made all the funeral arrangements for me and got that all taken care of.*

*A: What was that like?*

*Q: Well, it wasn't- it wasn't too bad. We just talked about what we wanted to be done at that time.*

This interaction was another moment when I became painfully aware of my own biases. I thought: surely, if she and her brother were talking about her death, there must have been sadness present in the room. Although funeral arrangements are logistical aspects of dying, the subject matter of death was an explicit matter between Quinn and her brother. I assumed that it would be an intense emotional moment.

*A: Wow....OK. How did you feel when that was happening?*

*Q: Feeling what?*

*A: Anything. What were you feeling as- as he was making those arrangements?*

*Q: I was glad to get to- get to make them myself, so when I- when I die, they don't have to try to figure out what I would want. And my brother wrote it all down, so he keeps the record of what I want.*

As we talked more about her conversation with her brother, the difference between our assumptions became clear. I thought that the subject matter of funeral arrangements would evoke anxiety about death, and thereby create tension in her conversation with her brother. However, Quinn seemed to feel no anxiety. Death did not induce fear for Quinn, so neither did her conversation about funeral arrangements. It was only a logistical discussion. Quinn valued the communication with her family, especially because she would not be able to talk to them when she passes away. I asked Quinn whether she wanted to leave anything behind to her survivors. If she is gone, is there anything that she wanted to do before she will no longer be able to talk to others? Quinn responded:

*Well, I- I wrote a book after my father died. I wrote a b- uh- a thing about his life because I knew some of the grandchildren didn't get to know him too well. And I wrote- wrote that up, and they keep it. And uh, I wrote it- another one about how-how we- what we did when we were little and the things we used to do and play. And my brother made a- a story out of it and gave uh- each family two copies of the story. So they- they have something to read because my- some of my nieces and nephews- they read it and said they wanted to get- read more of it. So they were very interested in what I wrote.*

Although Quinn felt no fear about dying, she thought it was important to tell a story about her experiences with her father. It mattered to her that his grandchildren (her nieces and nephews) would otherwise forget what she and her siblings had done with her father. Given that her parents and four of her siblings have passed away, she felt responsible to tell stories about them so future generations can remember them.

As Quinn responded to my questions, I noticed that those stories focused on her father. I knew that she valued the relationship with her family, so I was not surprised to learn that Quinn wanted to keep a record of her family. However I wondered if she also wanted her own legacy to be told. In response, she simply denied that there would be anyone who wanted to write about her. However, Quinn told me that she wants to be remembered for the things she had done with her family. Given that she felt close to her family, it made sense that her telling the story of her family sufficed in telling her own story to the future generation.

The stories she told about her father also involved what she did with him, so she was going to be remembered for the events that transpired between her and her father. Writing about her father was not

an action she did after she started thinking about her death. However, writing her father's story seemed to serve one purpose she would not be able to fulfill after she passes away, which was her wish for the family to be remembered.

What role did her intimate relationships play in Quinn's death acceptance? Quinn was a person who had well established relationships and had little trouble accepting death. For Quinn, death meant that she was going to heaven or hell. Because she devoted her time to the family, she knew that she was going to heaven. Hence, death was not an event that compelled her to act in a different way towards her family. As she valued the relationship with her family, Quinn took actions throughout her life for the sake of what she considered valuable: for her family's legacy to be remembered.

**Member Check.** Quinn never thought that a member check was necessary. At first, she told me to go ahead with what I had written and see if I can “get a good grade.” As I explained that I would hate to represent her inaccurately, she invited me into her room within the nursing home. I read her my analysis, to which she only replied that I seemed to have gotten everything right. As I thanked her for her participation, she wished me luck in getting a good grade for what I had written, in her nonchalant language.

## **Discussion**

### **Summary of findings**

In this study, I explored, with four participants, the role of their intimate relationships on the process of accepting death. While they all told unique stories, their stories showed that there were some common patterns in the ways death acceptance and intimate relationships influenced each other. For some participants, if their relationships were already deep, they accepted death more easily. Others had to deepen their relationship before accepting their mortality. Furthermore, accepting death was a process, and not an endpoint. Although all of them came to the point where death was less threatening to the self, some of them continued to fear death for its implication for other people.

Brian needed to realize his connection with other people to become more accepting of death. In his earlier years, Brian's various diseases reminded him of death, which he found terrifying. He realized his connection with others by converting to the Christian faith after contemplating suicide. Through his Christian faith, Brian became less threatened by death. His relationship with his wife became stronger, to the point that he saw her as an inseparable part of himself. Tammy did not find death threatening because of her Christian faith; she believed that she would join God when she died. Although she thought about what would happen after she died, it was more of an intellectual challenge. However, her brother's death prompted Tammy to worry about how her death would impact others, most notably her son. Her relationship with her son became more reciprocal after her brother's death, as she was able to tell her son of her need to hug him time to time. For Ed, his relationship with his wife needed to be stronger for him to accept this condition, much as Brian. Ed started thinking about death when he was diagnosed with Parkinson's disease. In response, Ed wanted to die in a way that would not be burdensome to others. As he adjusted to his disease and decline, Ed's relationship with his wife became stronger. He recognized the importance of his wife and came to appreciate her presence more, to the extent that he also saw that she was an inseparable part of him. Quinn only started thinking about her own death as she reached her mid 80s. Even as she started to think about death, Quinn did not express a fear of death. Furthermore, her relationship with her family did not change. She was confident that she would go to heaven, as she tried to be good and help others. In particular, she devoted much of her time taking care of her ailing parents. As she knew that she was good, she was hopeful she could go to heaven.

Based on the findings, I first will discuss the gender implications in the study and explain the factors involved in the difference. In addition, I will identify the relational losses in the participants' lives, and talk about their influence towards death acceptance and intimate relationships. I also will



argue that, as participants' understanding of death became more experiential, their intimate relationships also became experiential as well. Before discussing these implications, I will first consider some of the limitations to the study.

### **Limitations**

The participants in this study all identified as Christian. Future studies may investigate how intimate relationships affect death acceptance in populations that are not Christian; in this study, the participants' Christian faith played a significant role in their death acceptance and intimate relationships. For example, Brian accepted death by becoming a Christian, and his Christian faith led him to deepen his relationship with others. Tammy's Christian faith aided her in believing that the dead will join God in peace; she also indicated a strong bond with her religious community. I expect the death acceptance and intimate relationships of those who subscribe to different religions to be different from those I found in this study; previous research indicates that different religions have different views towards death, and that the degree of religiosity affects the depth of relationships. Harding, Flannelly, Weaver and Costa (2005), for example, found that belief in God and belief in afterlife have a positive correlation with death acceptance. Hence, religious communities that do not believe in God or afterlife will have a different way of confronting death than communities that do. Furthermore, Falkenheim and Handal (2003) found that intrinsic religiosity and death acceptance had a positive correlation among older adults, suggesting that those who are religious may have a different way of confronting mortality than those who are not religious.

Furthermore, there is a possibility that religiosity influences death acceptance and intimate relationships. Labun (1988), for example, argued that religion and spirituality produce actions that demonstrate the feelings of "love, faith, hope and trust" (p. 315). Ellison and George (1994) also found that frequent churchgoers report more enhanced perception of social support than those who do not go to church. Furthermore, Rote, Hill and Ellison (2012) found that religious attendance is associated with higher levels of social support and lower levels of loneliness. The degree to which one is religious or spiritual hence seem to have an interpersonal component; more religiosity may make it more likely for one to engage in a deep relationship with others. Based on the findings of this study, those who have cultivated relationships also may be likely to accept death as well. Hence, religious beliefs may lead to deeper relationships, especially when they involve beliefs in an afterlife.

In addition, the participants were all retired older adults. Some of the participants started thinking about death in their late adulthood, which led their relationships to grow stronger. For example, both Brian and Ed started thinking about death after they retired from the jobs. In facing their mortality, Brian and Ed came to appreciate or deepen their relationships with their wives. The role intimate relationships play in the process of accepting death may look different for people in early adulthood whose relationship history would be much shorter than the participants in this study. For example, Lang (2001) found that older adults have a tendency to deliberately end relationships with less close acquaintances as they get closer to death. Furthermore, they found that as older adults approach death, they tend to invest in partners they have known for more than six years. Furthermore, Vam Groenou, Hoogendijk and Van Tilburg (2012) found that the size of one's interpersonal network decreases as people become older. One pattern that they found was that older adults are unable to replace the loss of their long-term relationship with new relationships. In other words, new and short-term relationships are limited in their ability to fulfill the relational need of the person as he or she becomes older. Some of the participants in my study interacted with their loved ones as husbands or mothers; younger adults have fewer opportunities to be in such roles. The participants in this study had either established or came to cultivate intimate relationships that played a role in death becoming a less threatening event. In contrast, younger adults may lack opportunities to cultivate such intimate relationships. If intimate relationships play a lesser role in accepting death, younger adults' process of

accepting death may look different from the participants in this study. Hence, younger adults may be one new target population. The future studies would provide an interpersonal explanation for Wong, Reker and Gesser's (1994) finding that older adults were more accepting towards death than younger adults. By expanding our knowledge of death and intimate relationships, we will see how death and intimate relationships manifest across the life span.

### **Gender Implications**

From the summary, there seems to be a gender implications in the ways in which intimate relationships affect death acceptance. Brian and Ed needed to strengthen their relationships before death became less threatening, whereas Tammy and Quinn who already had strong relationships and accepted death more easily. The differences in relationality in how people see themselves may explain the pattern. Researchers (Cross & Madson, 1997; Markus & Oyserman, 1989) have observed the ways in which women in the United States tend to have a more relational definition of self than men. That is, females tend to construe the self as more interdependent and group oriented than men. Cross, Bacon and Morris (2000) found that persons who subscribe to the relational sense of self tend to respect the need of others when making decisions. Furthermore, partners of persons with relational views evaluated their relationships more positively than those individuals who saw themselves in less relational terms. Utz (2004) also found that those with interdependent senses of self tended to be higher in social cooperation than those with independent senses of self. Hence, given the relational views of themselves, females tend to be better at cultivating deep relationships. The female participants of this study may have seen themselves as more connected to their loved ones, thereby being able to accept death easier than the male participants. By having a self more connected to others, they may have become less concerned about their own death and concerned more about the implications for others.

Previous research tends to be mixed in their findings of gender implications in death acceptance. Some found that older women tend to have higher degrees of death fear than men (Depaola, Griffin, Young, & Neimeyer, 2003), whereas others found that women were more accepting of death than men (Wong, Reker, Gesser 1994). Dattel and Neimeyer (1990) found that women scored higher on death anxiety. I should also note the difference between the two female participants as well. Although Tammy became tearful as she started thinking about what her death implies for her son, Quinn remained calm as she told me about her survivors. In other words, although both participants showed concern for her surviving family, Tammy was more visibly upset than Quinn. While Tammy and Quinn shared similar qualities, such as their gender, acceptance of death, and established intimate relationships, they also differed in their age. Tammy was still living at home with her son, whereas Quinn struggled between life and death. Such factors complicate the gender implications towards the attitudes towards death. Furthermore, there are conditions that may have affected this gender implications. The male participants in this study both complained of their physical ailments, depending on their spouses to take care of them. Before realizing the crucial role that their wives played in their lives, both participants did not think of being as important as they do now. Furthermore, Tammy was divorced and had a tumultuous relationship with her former husband; Quinn was never married. Hence, the difference may lie not so much in the gender of the participant, but could be related more to whether the participant is married. In terms of marital status, Cole (1978) did not find any significant results on death anxiety and marital status. Based on the results, I find it important to investigate how marital roles and gender affect death acceptance and intimate relationships. Future studies should include men and women who are single, those who are married, and those who are divorced.

### **Relational Loss, Death Acceptance, and Intimate Relationships**

Through the analysis, I found themes that were common among all interviews. First, I found that, for some participants, there is some major relational loss, followed by becoming more aware of death, and affects their future relationships. Tammy lost a family member. Brian and Ed lost their

occupations and the relationships with their co-workers and customers. Following these events, participants became more aware of their own death. The sequence of one's relational loss followed by a change in one's own attitude towards death is reminiscent of Imara's (1967) observation of Miss Martin who started to accept death as others started to affirm her presence. For these observations, I found the constructivist explanation helpful in understanding the process of how relational loss may lead to more death awareness. Kelly (1955) has stated that, if we experience a major loss, we experience a disruption in the continuity of the construct system (Neimeyer, 2004; Rowe, 1983). The major disruptions may have led the participants to think about how vulnerable their construct systems are. Before the disruption, their construct systems seemed to be secure. They could go about living their life according to the construct system they had built. However, with death, they may have faced an event that did not fit with their usual way of construing the world, thereby making them question whether their construct system is a useful one. As the participants questioned the validity of their construct system, they may have become more aware that our construct system can eventually cease to be, making them more aware of death. Based on this thought, a new study may shed light on whether disruption of lives leads to questioning of old life values, and whether such reevaluations of life lead to more death awareness. Researchers may ask people who have experienced a loss, and then ask them about any possible change in their life values. Then, they may ask whether they became more aware of death as they reevaluated their life. Previous research seems to support that the patients do evaluate their lives after they experience shocking experiences. For example, Dickerson (2002) interviewed patients who had gone through a sudden cardiac death experience. The overall pattern she found was that patients tended to redefine their meaning of life after their death experiences.

For many, death is the biggest change in one's construct system, as it implies the end of meaning making (Kelly, 1955). Kelly himself stated, "If death is incompatible with the construction system through which one maintains a basic orientation towards events and their anticipation, then the like elements in the context of death are threats" (p.116)." In Kelly's framework, death can be the most threatening event to many. For Brian and Ed, death was at first very threatening. However, after deepening their relationships with their wives, they eventually becoming more accepting of death. As they felt vulnerable with their construct system, they may have felt the need to construe themselves in more relational ways. By reconstruing them in relational terms, their relationships with their wives became much deeper. Tammy already had a close relationship with her son, but it became deeper as she thought about the impact of her own death on her son.

I hence saw a pattern in which relational losses affected the participants' death awareness, followed by the deepening of the relationships, and then the accepting of death. Does the type of loss affect how the person becomes more aware? Future studies can seek whether different types of significant loss or trauma affect people to be aware of death in different ways. Surprisingly, the research on trauma survivors and death acceptance has been scarce (Florian, Mikulincer & Green, 1993). In the scarce literature, however, Abdollahi, Pyszczynski, Maxfield, and Luszczynska (2011), found that the degree of "peritraumatic dissociation" affects the degree to which earth quake survivors accept death. By "peritraumatic dissociation," the authors meant the experience of feeling as if the traumatic event was unreal. Trauma survivors often describe their traumatic events as happening in slow motion, or that they felt disconnected from their body. Among survivors of the 2005 Zarland earthquake, high peritraumatic dissociators did not defend against mortality reminders as much as the low dissociators. New studies can ask in open-ended ways how different kinds of trauma affected the attitudes towards death. Specifically, researchers may ask people to describe their most significant loss. They could then assess whether different types of losses lead to differences in the relationships between death acceptance and intimate relationships. Such findings will substantiate the proposed model that major disruption is followed by increased death awareness and the deepening intimate relationships.

Unlike the other participants, Quinn did not experience a significant change in the way she felt about death after she had a major loss. One explanation is that Quinn did not perceive her losses as “disruptions” in her life. The deaths of her father and mother were compatible with her construct system, as she said that it did not bother her when they were dead. Furthermore, she also expressed that she lives according to her Christian values, which reassured her that she will go to heaven. Hence, I found that having intimate relationships beforehand and having Christian faith facilitated her acceptance of mortality. Quinn hence did not express fear of her own death. She told me that she saw death as going either to heaven or hell and that doing good will grant her entry into heaven.

### **The Experiential over the Intellectual**

Through the analysis, I realized that I can distinguish between different kinds of death acceptance. On the one hand, there is the intellectual, cognitive way of accepting death. Whether it was based on religion or not, participants spoke of what they think happens when they die. Tammy said that her soul will join God, specifically designating her thought as “intellectual.” On the other hand, there is the emotional and embodied understanding of death. I collapsed “Emotional,” “experiential,” and “embodied” under the same category because I understand emotions to be an embodied experience. Furthermore, the participants were more expressive with their emotions especially when they talked about their personal experience related to death, as opposed to the times when they talked about their cognitive beliefs about death. For example, both Brian and Tammy became tearful as they talked about the experience of losing family member.

I found that the emotional, embodied acceptance of death, rather than the intellectual acceptance of death, had a more significant influence on the participants' relationships. Tammy was the most exemplary of this finding. Tammy only thought of death as intellectual until her brother passed away. After his death, her death-attitude became more grounded in her personal experience. She then started to think about how her death would impact her son. Brian came to accept death in an experiential way as well. His attempt to drive himself into a tree was an action, rather than a theoretical thought. The action and the subsequent embracing of Christianity eventually led him to realize the absurdity of throwing his life away and become more accepting of death.

My finding about embodiment was consistent with constructivists who have stated that the intellectual understanding is secondary to our experiential understanding. Developmentally, we first make meanings through our bodily interactions before our verbal intellectual engagement with others. Bohart (1991), in particular, suggested that we experience the world primarily through experience, rather than through concepts. He hence stated that our intellectual understandings are only secondary to experiential understanding. Leitner and Faidley (2003) also stated that it would be a misinterpretation to think of “personal constructs” as being only theoretical and cognitive. They have stated that our bodies are vital carriers of core constructs. According to theorists such as Bohart, Leitner, and Faidley, we engage in meaning making primarily through bodily and emotional experiences. Their theories applied to the participants in this study, whose death acceptance was affected more by personal experiences related to death, rather than the intellectual theories of death.

The finding leads me to wonder, in the context of death acceptance, is there a difference between those who believe that their body is an integral part of their identity and those who do not? I expect there to be a difference in the way death is accepted by people who believe that their body is a core part of themselves and people who do not believe in it. While I found that embodied acceptance of death affected the participants more deeply than the intellectual understanding, I did not assess the extent to which the participants saw their body as an integral part of themselves. Events more meaningful to people who cherish their body, such as acts of physical intimacy and maintenance of physical health, are less meaningful to people who do not identify with their body. If people do not think their bodily function is a core part of themselves, then signs of physical decay, such as moving

slower, may not make people accept death like the participants in this study.

Furthermore, I expect the belief of what happens to the body after death to affect the relationship between identification with one's body and death acceptance. Haddow (2005) conducted a study in which she interviewed donor families and investigated their death views and whether they donated organs of their deceased family members. They found that donor families who believed that death separates the soul from the body were less hesitant donating their deceased's organs to others, while the opposite was the case for those who believed that the personal body is connected to the interior of the self. From Haddow's (2005) finding, I expect that the dying person's own beliefs about his or her body would have an influence on the degree to which death is a threatening event. If death only means that the soul separates itself from the body, then the person would not feel threatened by death, especially when he or she does not identify with the body in the first place. This person would have a different way of confronting death than someone else who believes that death means the end of life in any form, especially when he or she identifies with the body. Hence, I expect that beliefs about what death means for the body affect the way one confronts mortality. In the proposed study, I would ask the participants what role the body plays in his or her daily life, and what they think happens to the body when they die. Then, I will ask about how the participant feels about his or her death.

The participants' physical interactions with loved ones increased as they became aware of their deaths in an embodied way. Tammy's story was the most exemplary. On the day of her brother's funeral, she made it explicit to her son that she wanted him to be comfortable with her hugs. Since then, Tammy and her son are able to hug each other with comfort. For Ed too, as he started to notice the physical difficulties, he felt closer to death. As he became more aware of death, his relationship with his wife became more embodied as well. From helping him change clothes to navigating around the house, his wife became essential for Ed to be physically active in this world.

From this conclusion, I wonder whether sexual activity is another embodied experience that could lead people to be more death accepting. Sexual activity can be a great expression of intimacy, especially for older adults. Lodge and Umberson (2011) found that later life husbands and wives tend to have more congruent experiences of marital sex. As couples grow older, the gender inequality in the relationship tends to decrease to the extent that the women do not feel obliged to respond to the sexual desires of men. In a more gender-equal relationship, men and women feel less need to live up to the standards associated with their respective gender. Hence, despite the decrease in the frequency of sex, the quality of sex tends to increase for older couples.

Furthermore, Goldenberg, McCoy, Pyszczynski, Greenberg, and Solomon (2000), found in their quantitative study that death reminders led to an increase in sex interests. One interpretation of this finding is that, as the participants became more aware of death, they sought to satisfy their relational needs by sexual activities. In response to the findings by previous researchers (Lodge and Umberson, 2011; Goldenberg, McCoy, Pyszczynski, Greenberg & Solomon; 2000), in a new study, researchers can ask the participants about the meaning of sexual activities, how their sex lives have changed over the years, and whether it connected to their attitudes towards death. The proposed study may add a relational component to the literature with the finding that people have sex and deepen their relationship with their loved ones in order to confront their mortality.

### **Clinical Implications**

The findings in this study also have clinical implications. In this study, death affected each person and his or her relationships in different ways and their relationships affected their views toward death. For clients who attend therapy for concerns about their terminal illness, the therapist and client may have a discussion of what it means for the client to die. Much as Brian who initially felt threatened by death, some clients may have difficulty accepting their terminal illness. In response to their difficulty, the therapist may help them accept their death after deepening of intimate relationships,

much as the participants in this study. If the client already has an intimate relationship, then guiding the client to see the role that the loved one has played over the years may help the client to appreciate the value of the person, thereby deepening the relationship. If the client feels that he or she does not have an intimate relationship to begin with, death may be a particularly difficult event to accept.

In one example, Smith-Pickard (2008) discussed a young client with a short prognosis who wanted to make it to her 18<sup>th</sup> birthday. Smith-Pickard noticed how withdrawn and tired she looked in the hospital bed. However, when the client received a phone call from her father, her voice suddenly became cheerful. To her father, the client sounded optimistic about her illness, reassuring him that she will be able to come home soon. As soon as the phone call ended, the client returned to her usual heavy mood. Smith-Pickard asked the client what it was like for her to look cheerful for everyone else when she necessarily does not feel cheerful. The client spoke, "It feels like I am going on a long journey and nobody is coming with me" (p. 138). In response, Smith-Pickard sought to make death less of a lonely event for her client by having her share her feelings about death. She found that it was meaningful for both herself and the client to talk about death as painful and scary as it really felt.

Consistent with the finding of this study, a client can confront death easier with the deepening of the therapeutic relationship. Smith-Pickard (2009) makes the point that we live in a culture where only a few of us are prepared to talk about death. The dying person may be in a lonely place, especially when he or she feels the need to act according to others' expectations. The therapeutic relationship will become meaningful when the therapist can be intimate with the client, by being in the same emotional "place" as him or her, much as Smith-Pickard did.

In addition, the study may have implications for termination issues. In this study, talking about death led the participants to reflect upon the value of the relationship with their loved ones. The participants realized how important their family members were, as they thought about what their deaths mean to them. Termination and death are similar in that both of them imply a major change in the construct system of the client and the therapist. The therapist and client will no longer be sharing the same place and time, much as the participants who either lost a loved one or will leave their loved one behind. Given that it is a major change, clients may have difficulty accepting the end of therapy. Leitner (2009), for example, discusses denial, minimization and emotional overwhelm as responses that clients engage in response to termination, which resembles Kubler-Ross's (1969) stages of death acceptance. Leitner argues that, the client may deny or minimize the pain of separation by canceling appointments or intellectualizing the conversation. The client may even attempt to continue the relationship by looking emotionally overwhelmed, thereby displaying the need to continue therapy.

In response to such difficulties, however, Leitner suggests that the termination process is an opportunity to celebrate the meaning of the relationship. One would not grieve if the relationship was meaningless. If the client has difficulty accepting the end of therapy, the study suggests that deepening the relationship may help clients to confront termination. The therapist and client may be able to recount the history of their relationship, assess the changes in the course of the therapy, and exchange appreciation for the relationship that they developed. If the deepening of the relationship is an embodied experience and facilitates a relational way of understanding oneself, the client will find it easier to accept the end of therapy. Previous researchers have also attested to the importance of therapeutic relationship in termination, finding that it is key to feeling positive about the therapy (Baum, 2007) and that it provides a counterpoint to other traumatic ends of relationship (Anthony & Pagano, 1998).

### **Final Thoughts**

Hopefully, the growth in the research on death attitudes will inspire the public to have more open conversations about death and the importance of relationships. Hardwig (2004) argued that the dying have the obligation to think about how their death should affect their loved ones. As the participants'

stories showed, their dying processes certainly had implications towards the participants' intimate relationships. However, the conversations about death should not only be among those who are diseased and dying. As death awaits all of us, increasing our awareness towards death may change the way we interact with our loved ones. Hence, death-acceptance and intimate relationships are topics that will continue to be relevant to all of us.

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## Appendix A:

### Informed Consent

This study explores how death-acceptance affects intimate relationships. Should I agree to participate, I will be asked to engage in an interview in which I discuss my views on death and how they affect my intimate relationships.

I understand that if I agree to participate, I will engage in two interviews. Each interview will last 30 to 60 minutes. The second interview is expected to take place one day after the first; however, I understand that the time in between interviews depends on my preference as well. In addition to the two interviews, I will meet with the researcher one last time to confirm that there is no discrepancy between my response and his analyses. I understand that my participation is completely voluntary. I understand that I am free to discontinue my participation at any time without penalty. I may also skip any questions that make me feel uncomfortable. Even if I withdraw from the study, I understand that I will receive any entitlements that have been promised to me in exchange for my participation.

I understand that, if I wish, I may obtain written information about the outcome of the research at the end of the academic year. Upon request, I may receive a copy of the results via email or post.

The present research is designed to reduce the possibility of any negative experiences as a result of participation. Risks to participants are kept to a minimum. However, if my participation in this study has caused me concerns, anxiety, or otherwise distressed me, I understand that I may immediately notify my caretakers.

I understand that I will be given additional information after my participation is complete.

I understand that all data from this study will be kept from inappropriate disclosure and that the data will be accessible only to Aki Imai, the project supervisor (Dr. Larry Leitner), and any persons who may assist with transcription. I understand that neither my name nor any other directly identifiable information will be included in the final manuscript.

I understand that, if I wish, I may obtain written information about the outcome of the research at the end of the academic year. Upon request, I may receive a copy of the results via email or post.

The possible benefits of participation in the present research are that participants may learn more about how psychological research is conducted. Specifically, the participants will have the opportunity to learn how their responses are observed and analyzed.

I understand that I will be provided with a blank, unsigned copy of this consent form at the beginning of the study.

I understand that I am free to discontinue my participation at any time without penalty. I may also skip any questions that make me feel uncomfortable. Even if I withdraw from the study, I understand that I will receive any entitlements that have been promised to me in exchange for my participation.

Should I have further questions about the study, I understand that I may contact the experimenter, Aki Imai, through the research supervisor (Dr. Larry Leitner, (513) 529-2410) in the Department of Psychology at Miami University if I have any questions or concerns regarding my participation in this study. If I have any questions about participant's rights, I may contact the Office for the Advancement of Research and Scholarship at (513) 529-3600.

Thank you for your participation. We are very grateful for your help and hope that this will be an interesting session for you. You may keep this portion of the page.

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Cut at the line, keep the top section and return the bottom section.

I agree to participate in the study of death-acceptance and intimate relationships. I understand my participation is voluntary and that my name will not be associated with my responses. By signing below, I acknowledge that I am 18 years or older.

Participant's signature \_\_\_\_\_ Date: \_\_\_\_\_

## Appendix B

### Interview Protocol

The researcher will keep in mind that the questions on bullets are only asked when the participants are not able to elaborate.

#### Interview Day 1: Death-Acceptance:

Could you talk about what death is going to be like for you?

What does death mean to you?

How are you acknowledging death?

What will happen to you when you die?

Tell me what comes to mind when you hear the word death.

Do you have fears associated with death? Describe them for me.

Tell me about death as it will happen to you and then happen to others?

#### Interview Day 2: ROLE relationships

Could you talk about the most important relationship/friendship in your life?

What kind of relationship do you have with this person?

Who is it?

- Tell me about this person

How did you get to know this person?

how much do you know this person

how has he/she/it affected you in your life?

- What role have you played in this person's life
- Have you expressed to him or her how you were affected?
- Could you give an example?
- Could you tell the story about the most memorable thing in your relationship/friendship/friendship
- How have you affected his or her life?

#### Death-Acceptance X ROLE relationships

How have your views on death affected your intimate relationships?

what kind of relationship did you have before you acknowledged death as a close event

what kind of relationship do you have since you acknowledge death as a close event?

what kind of story will you leave behind to him or her?

Is there anything that you would do differently in the relationship?

## Appendix C

### Brian Interview #1

Aki (A): So could you uh, talk about the time um, that you entered the nursing home? How you entered this place?

Participant (B): Yeah, I uh, I had problems of falling at home. And uh, they- I lived with my son and my daughter-in-law, and they didn't want me to fall and them not be there. And uh, anyone wasn't there, uh, take care of me. So I had fell several times and was there by myself, and uh, so they uh, the doctor decided it would be the best to put me in here- in a nursing home, where I could be taken care of and uh, because I had lost my wife with cancer. And uh, and I was living with my son. I- I'd let him have my home, and um, was living with him. So uh, they put me in here, and in-in January. I'd been in here seven months. And uh, it's really been good. I've-yeah-I-I-I believe uh, I believe that God put me here for a reason, but I've been able to communicate with people that-that can't understand that they have a Alzheimer's, you know. And um, and I can seem like I can get through to them, where the others can't get through to them. And they talk with me and everything. So I-I-I'm really pleased to be in here. And I have a, I have a condition of the Parkinson's, which I-I have spells real bad sometimes. Yest- uh- Wednesday we went to the county fair in Butler County. And they-they wanted me (laughs) to go. And I said, "You sure you want me to go? I may-I may not be able to go-uh, take it." You know? And they said, "Yeah we're-we-we'll be with you. We want you to go." So...

A: Who-who was it that was inviting you?

B: That was the activities lady. And um, so we got in the van, and we went (pause) to the county fair. And got on the highway, and we didn't have any air. And the air conditioning-the air conditioner wouldn't work. And I said, "Oh my Lord." So uh, it got pretty bad, and then uh, the fumes from the exhaust started coming inside, and I can't take fumes. And uh, so yeah, we pulled off and let the one boy got sick. They let him get out and walk around a little bit and put him back in. I said, "Let's go on. Let's go on." So we went on. We went to the county fair. We got down there, and it was so hot. And they-we were in wheelchairs. They were pushing us in wheelchairs down through the fair ground. And we- (laughs) we didn't get to see much. We didn't get to see much. We went all the way down to the- eh- to the- the- a- arena, where the- the uh- a- arena, like where the seats were for the racetrack and everything. And we sat there and rested a while, and she decided we better go back home. So...

A: How long were you there for?

B: Huh?

A: How long were you there for?

B: Uh we got back here at one o'clock. We left here at nine. And uh, so we started back. They pushed us back to the van. They went and got the van where we loaded-unloaded at and brought it up there, and we loaded up, started back home. And we got in McGonigle- that's just out of Oxford, it's south. And it overheated. We had to pull off. And they had to call for help. (laughs) So we got um, the mechanic here. He came down and- and then one of the office ladies brought a Cadillac that the company owns here. And I was getting bad. I was-the Parkinson's was kicking in, and I was overheated. And um, they had cold rags around my neck and on my face, and- and I thought, "Oh boy. This is going to be a mess." But they put me in the- in the Cadillac and brought me back. And they

brought me and put me in this chair. And then I had one of my spells. I was out of it then the rest of the evening. But uh- I- I made it. I made it.

A: Wow. That's very impressive.

B: Yeah. And they brought the van. The mechanic brought the van back, and uh, after it cooled off. And- and unloaded the rest of the guys. But it was an exciting thing, and uh...

A: I bet it was.

B: I said it will go down in history. (laughs)

A: It sure will. (laughs) You said now you had one of those spells when you got back here.

B: Yeah.

A: What did you mean by that?

B: I have uh, I have- I- I go out. (pause) You know. Pass out. And I can't talk. I can hear, but I can't talk. And uh, I shake. I shake real bad, you know- all over. And uh, they just laid me back in the chair- laid my chair down and laid me back in the chair. And give me a medication to-to kind of knock me down a little bit, you know. And uh, and then I- I laid there until I got over it. It's almost- it's almost like some seizures, if you know what a seizure is.

A: Sure.

B: It's almost, but it's worse. It's worser than a seizure. It lasts longer. And now the medication they give me- Ativan. Ativan. It is a nerve pill, and it kind of knocks me down for in about- about three hours uh, I'll come out of it. And so, it- it was uh- it was kind of exciting. But I- I can say I went to the fair.

A: Yes, yes you can.

B: (laughs) I didn't see much. (still laughing)

A: Right, but you went out.

B: But I went out. And it was four of us that went. And uh, and then we had the- we had the staff. It was four of the staff to push the wheelchairs, you know. And uh, we didn't get to see anything. We really didn't get to go in a building and see the livestock and all that. That's what I wanted to see. We didn't get to see it. But everything turned out alright. I got back home safe. And that was the main thing.

A: Yeah. Could you uh, talk about dealing with the Parkinson's when you were first diagnosed? How did you feel?

B: Okay uh, (pause) when I- when I was first uh- uh. They found Park- that I had Parkinson's, um, I



had- I had uh, I had seizures when I was eighteen years old. And all the way up until 1986. At nineteen, I had been in the service, and I had seizures when I was in the service. And uh, when I'd come home, (pause) um, I still had the seizures. 1986 um, I got rid of the seizures. The seizures uh, quit on me. And uh...

A: Did you- were you seeing a doctor at the time? Or did it just stop?

B: Yeah, I had doctors at the time uh, working on me all the time. And uh, so they uh, they said, and at this point I had open-heart surgery. I had a stroke. And then after the stroke, I had open-heart surgery. And when I had open-heart surgery, then I started this here Parkinson's. I started shaking real bad. And uh, I don't know uh, really what caused the- the Park- of course my family, in run in my family. My dad had Parkinson's, and my two brothers had Parkinson's. They both died with Parkinson's. And uh, I had two sisters that had Parkinson's. So it kind of run in the family. Now I- I- I don't know what caused it. (pause) But uh, they put me on a medication in the VA hospital. That's the veteran's hospital. Uh, they put me on a medication. And they- for Parkinson's- and uh, it didn't work. It bothered my heart. And uh, I- I about I- I couldn't- couldn't make it, so uh, they took me off of that. And they put me on another one. There was three medications that they had for Parkinson's. And so they tried all three of them. And the one made me just crazy. You know, it just made me- I was real crazy, the last one that they put me on. So they uh, my son told them said, "Don't give him no more." So they took me off of that one. And they said, "Well, there's nothing that we can do for it." So I've had it ever since. And uh, it really never got this bad where I've had these kind of attacks- until I got in here. And uh, when I got in here, I had uh, I had kidney stones real bad before I came here. And they blasted those kidney stones and got them out of me. And um, I don't know whether that might have set it off. Uh, or I- I got worse, but I got to where I was really having fits, you know, just really having fits.

A: So it must have been very difficult.

B: Yeah. And I couldn't- I couldn't handle myself. So they get me either in the bed and um, put a pillow across my chest, and I beat on that pillow because I- I beat myself pretty bad.

A: You beat yourself?

B: Yeah. And I pull my hair. I pull- uh- I- I pulled my hair. I had long hair at the time. I mean my hair was pretty- pretty long, you know. And I pulled my hair out. I just pulled big chunks of it out because of the pain in my head and uh. So they uh, they took me to the hospital, and they gave me a shot of this Ativan. And that's a nerve- nerve medicine. And it knocked me out. The shot that they gave me is really better than the pills they're giving me now because it- it knocked me out. It did- I went clean out. And it- it knocked me out quick. I know the nurse told me when she gave me the shot at the hos- hospital she said, "Two seconds, and he won't know it, nothing; he'll be gone." So uh, it knocked me out. But now these pills don't knock me out. They- they just calm me down. And uh, and I go down slowly.

A: The pills that you're taking here?

B: Yeah. It takes longer for them to work. The pills. So uh...

A: Ok, um, if I could stop you for a second.

B: Yeah.

A: Um, so you said you're relatives- your father um, they died- died of Parkinson's. Um, does having Parkinson's remind you of um, death?

B: Of death?

A: Right.

B: Yeah. Uh, because my uh, knowing that my dad died, he had it. And uh, my uh, (pause) one brother, one real older brother had it real bad, and he died with it. And I stayed with him, and you know, watched him go. And- and uh, my other brother, he got it, and he was real bad. He was ninety-one. And uh, they had- they had to strap him on the bed. He got so bad that he was like me. He- he had- he had fighting in him, you know, where you fight yourself. And uh, they had to strap him down. He lived in North Carolina. And they had to strap him down in the nursing home- he was in a nursing home. And uh, he- he finally died. And so, my two sisters had it, and both of them died. And uh, but they didn't have it that bad. They didn't have it as bad as what I've got, or what my one brother had. But it uh, it bothers you. Um, course I- I- I really am not afraid of death myself because I'm a Christian. And- and I believe in God. And uh, I put my faith in God. So I really uh, don't f- don't fear uh, death as bad. But uh, you- you think about it. You know, you think I watched my wife- I held my wife's hand until she passed away, and I've seen- I've seen a lot of death in my life. And when I was a young boy, it scared me to death. We- we would go- we would go visit people that were dying. And uh, it's uh- I would come home, and I'd have uh, nightmares, you know, at night. And because seeing somebody die that uh, it- it doesn't bother me now.

A: How- how did it change from being very fearful to not being afraid? How did it change?

B: Uh, the change came when I really got uh, saved uh, with Christ. Whenever I went to church, and I got saved, that's when the change came for me having a fear of dying. And I don't have it anymore. And uh, now when- when my wife had cancer, I- I fear- I feared I wasn't saved then. And I- I feared death. I feared death. And I feared for her. And I hadn't- I couldn't- go to sleep at night or nothing, you know. But uh, since I got saved, uh, Christ has took all that away from me. And- and I really- I- I don't fear death at all. If I was to get down right now, you know, and knowing I was going to die- it wouldn't- it wouldn't fear me a bit. It wouldn't fear me.

A: How did Christ take away that fear? Um, could you talk more about that?

B: Okay. Uh, I got in the word of God. I got a Bible. And I- I got in the word of God. And- and I- the Bible taught me about death- uh, the first death, second death. And all and- and I- I learned uh, reading my Bible- it uh- I didn't have to fear death after Christ would take care of me. And I have to pray and have faith in God, and if I've got faith in God, he'll take care of me. So that's- that's what's took it all away from me. If- if uh, if I was a sinner, uh, I- I- I probably would really fear death. I have uh- I have a friend, and he tells me, he said, "Man I lay down at night, and I dream, and I'm in a coffin- in a box, you know." And uh- and- and he says, "It scares me to death." And I said, "Well, uh, you can get with God. And- and you can get in that Bible and read. And it'll teach you, and you get that Spirit. And uh, and you won't- you won't fear that death. So uh, he now is a- is a- a deacon in a church. And he tells- he gets up and tells he don't fear death anymore.

A: Oh, wow. So you influenced him?

B: Yeah. And uh, I tell everybody, you know, once you- once you get born again, that's what the Bible says, once you get born again with the Spirit, uh, you don't have to fear death. Uh, and uh, it- it'll take that all away from you. So (pause) I tell the people here, you know, there's people here that's bad, real bad. And uh, I've been- I've been just showing my pastor, uh come and go while I was eating lunch. And he came, and uh, the lady was sitting down the end of the table there- she's got that Alzheimer's. And she's real bad. She's real bad. And they couldn't get her to take her medicine. And they couldn't get her- she'd fight them, you know- "Get away. Get away," and curse them out and everything. And I told my pastor, I said, "Watch." And I went down to her, and I- I talked to her and got her talking to me. She called me by- by my name. And I said, "I love you." And she said, "I love you too, Brian." So see, it's- it's- it's just a way God uses you. And uh, I- I- I'm just so grateful that one day that the Lord saved my soul, you know.

A: And you're passing on to others.

B: Yeah. Yeah. So...

A: So what does death mean to you? What is death?

B: What does death mean to mean? That one day I'll go to Heaven. If I lived good. If I lived good, according to that Bible, I'll go to Heaven. And I- and I won't have no more death. I won't have no more trouble, no sorrow or pain. I won't have nothing. I'll be a young person again.

A: Young person?

B: Young person. And that's what- what the word of God says. That we'll be born, and uh, in- in a new- new body. When he calls us all the great. And uh, so uh, that's what I'm looking forward to. Okay.

A: Very nice. Um, so how do you want to spend the rest of your life?

B: I want to spend the rest of my life talking to people, comforting people, helping people all I can. And uh, that's one thing that I've set my plan for. Since I've come in here, I can't go out. I can't, you know, I- they- my son can come and take me- sign me out and take me to restaurants or something like that, you know, and bring me back. Um, but I'm in here to stay. This is my home now. And uh, you could tell I have a room here- a nice room and everything. All my livable things is- is here that I- I need. And uh, so I have to forget the outside world. And- and think about what's in here- what's in this uh, rest home. So I put my life in this uh, in this place to helping people now.

A: So this is a last home?

B: Yeah. My last home here (pause) on Earth. My next home will be in Heaven.

A: Okay. It's a next step?

B: Yeah. Next step.

A: Thank you so much. You said um, living good is very important.

B: It is.

A: Um, and that's connected to having a good death itself.

B: Yes.

A: Could you talk about that connection a little bit?

B: What's that?

A: Uh, could you talk about like living good and that- how that connects to you going to Heaven?

B: Yeah. Uh, if I live good, and I don't sin uh, then God's got my name written in the book. And- and I- I'm uh, expecting to go to Heaven. And uh, and He- He- He- He said if- if you uh, live good and you don't sin, He- He said eternal life in Heaven. And uh, so that's- that's what I'm looking forward to.

A: You're looking forward to it?

B: Yeah. (pause)

A: Okay. (pause) Um, let's see. So could you tell me what comes to mind when you hear the word "death"?

B: What comes to my mind?

A: Uh-huh.

B: The word "death". Uh, when I- when I- what comes to my mind is seeing people around me that's not ready to go. That's really never been born again, in- in Christ. That's what worries me. That's what- I- I worry about them people. I- I don't worry about myself. (pause) But I worry about them people out there that's- that's not ready. And uh, if- if they're not ready, uh, I have- I have people here I talk to, and uh- and I know they're not ready. Because uh- uh- of the sinful things they do, you know- the language they use, the bad language and all that stuff. And uh, and I know they're not ready. And I feel in my heart that they're not ready. And so it worries me to know that- if they don't- if they don't get themselves right, the Bible says that they're going to burn in Hell. And uh, that's- that's sad. That's sad to know. If- if- to think that uh, people will go to Hell and burn, you know.

A: You feel for these people?

B: I feel for those people. And uh, I mean it's really sorrowful to know that- that your friend, even my children- my children (pause) uh, if they're not right, you know. Uh, all I can do is tell them. I can't- I can't take them to Heaven. And uh- I can't uh- I can't get them there. But I can tell them the right and wrong. And- and if they don't listen, then they know where they're going. So I've got a boy- I lost a boy two years ago in June in a motorcycle wreck.

A: I'm sorry to hear that.

B: And that boy is my oldest son. And he got on drugs at uh, twenty years old. Some girl got him on- got him hooked on drugs. And he got on those drugs real bad- couldn't get off of them. I tried- I tried for years to get him off them. And he- he got real bad. And he joined a motorcycle gang. And uh, and I just- I- there was nothing I could do. Wasn't nothing I could do. That hurt me so bad. And I laid at night. I prayed. And I cried. And I prayed over him. And uh, I couldn't change him. I couldn't change him. The drugs had him. And so he got into a motorcycle wreck and killed him. And that hurt me so bad.

A: That he was taken away from you?

B: Yeah. (pause) And that was my oldest son that I grew up. I grew him up uh- uh- he worked right by my side. He'd go right beside me everyday where I worked at the Boy Scout camp. And- and he- he learned everything I- I did, he learned it. And I taught him everything I could, you know. And then it just wasted- just wasted. And that really hurt me. That really hurt me. It was sad. But uh, there's nothing I could do about it. And uh, I know when it happened uh, they cremated him. And uh, I went to his funeral, the viewing. Uh, and- and I just- it was just hard for me to take. But I turned it over to God. And I said, "God, you have to help me. You have to help me get over this." And He did. He comforted me. And uh- and uh- I got over it.

A: He was with you?

B: Mmmhmm. (pause) So it's sad, pretty sad. But uh, but you have to let them go.

A: Obviously being as good as you is something that is very important. (pause) Okay. Um so, could you talk about your life a little bit? About what kind of life you lived um...

B: I've lived uh- uh not a bad life. I was raised up in a Christian home. And I lived uh, not a bad life. But I was in sin. And the Bible tells you you're born in sin. And uh, and I- I would drink. And uh, go out to parties. I played music. And uh, I had a band. I had a- I had a group. And I'd take that group of musicians, and we'd go play for them bars and all that kind of stuff. We'd done all that kind of stuff. And uh, but uh, I kept myself clean, as far as getting into trouble. I never did get in trouble. And uh, but uh, it- it- the places where I played a lot of times, there was a lot of trouble- (laughs) a lot of trouble there. And uh, when you go in a bar and you know they're drinking, and they get high, and uh, they get into fights and stuff like that. But I was always one of those people who could get out and get away from it.

A: You stayed good?

B: Stayed good. And uh, but uh, I was mixed up in it as far as being in there. But uh, I tried to keep myself safe. And uh, but still I was- I was a sinner. And uh, and my mother- my mother, she prayed for me a lot of times. And- and uh, the- my other younger brother played music with me. And we had two or three more that played music with us. And uh, she worried until we'd come home at night. And she'd be- she'd be uh, waiting for us to come in. And uh, to see if we was alright, you know. But uh, I worked hard. And uh, I had a hard life. I uh, we were poor. My family, we're poor. And uh, my dad was a farmer. And back then, the farmers were all you know, you just had to scratch to make it. And uh, so we

were poor. And like I said, there was fifteen of us kids in- in my mom and dad's family. And it- it was hard sometimes. But- but we made it. And I don't know- it seemed like it was more love in us uh, in one another, you know back then. And that's what kept us going. We had love for one another.

A: Okay. For your family?

B: Yeah. Our family. And uh, yeah, but we uh, now my older- my older brothers and sisters uh, had seen- seen it harder than I did because uh, back then uh, back then early uh, they didn't have the food and stuff like I had when I come into the world. Uh, things was just a little bit better. We had- I never did go to bed hungry. But uh, they did. They uh, went to bed hungry- the older ones. So uh, I- I lived uh, I don't know uh, some- sometimes uh, we got the wildlife. I used to love to ride horses and break horses. And uh, I- I go to rodeos and stuff like that. And that was dangerous- the things that I did were dangerous, you know. But I loved it. And uh, I hurt myself a lot of times. And I'd get right back out and do it again, you know. So I lived a pretty rugged life- (pause) in my time. But here I am today.

A: Right, right. Now- now that you're here...

B: Eighty-four years old.

A: Wow, wow.

B: Eighty-four years old. So uh, I thank God for that.

A: Uh-huh. Do you- do you see death as something that's close to you um, now that you're eighty-four?

B: Yeah. Yeah.

A: How do you feel about your life ending?

B: My life? I feel good. I feel good about my life ending. Yeah, I really do. I feel good. Um, they- my nurses here, they really feel sorry for me that they- they see me having these things and how I suffer. And when I come out of it, uh, some of them- well the one gentleman out there that's a nurse, he- he's almost in tears. And when he- when I- he comes in and sees me uh, after I come out of it, and he said, "Boy." He said, "I hate that to see you that way so bad." I said, "Don't worry about me. I'm alright." (laughs) I'm happy. I- I'm happy. I don't- I don't let it bother me. But uh, it's just something in life, you know. And if I was to die today, I- I'm- I'm ready to go. That's the way I feel about it. I have no fear. No fear. Like that- like that friend of mine that said he gets- feels himself in a casket, you know. And- and he said it just scared him to death. I know I sure don't- I sure don't fear about it.

A: Okay. Do you- do you ever fear- feel fear? Is it- do you always stay uh, do you always look forward to death? Or is there some times do you...

B: I don't even worry about it. I don't even worry about it. I never- I never let death enter my mind unless somebody talks to me about it. I never. And uh, I'm- He made my heart so calm. I'm just- I'm just calm with it, with life. And I take life as it comes and- and goes on. But it hurts me about other people. I- I- I hurt over other people. And uh, I see those people out there that's sick. And it- it tears me

up. It really does. I lay in my bed sometimes here and cry and pray for um, for them. And uh, because uh, I don't worry about myself, but I worry about them. And uh, I don't know whether they're ready to go. And- but death is something- it uh- it- it doesn't bother me. But it bothers me for them, you know. I worry about them- (pause) out there. And it-it's just- it's something. Since I've become a Christian, I have changed my life altogether. And uh...

A: So you changed into becoming a Christian? Was there a point in your life where you turned Christian?

B: Yeah.

A: How did that happen?

B: When- when I was Christian uh, how did it- how did it change my life? When I become a Christian?

A: Right. How did you become a Christian?

B: Yeah. I went to church one night. Well I'll- I'll go back to the first of it. (pause) I was sitting on my porch one day, and that's- that's when I had the stroke. I had the stroke. And I couldn't do anything. I was paralyzed on this one side. And...

A: This was what- how old? How old were you when this happened?

B: I was probably in my sixties. (pause) And uh, early sixties when I had the stroke. And they wouldn't let me work no more. Doctor took me out, made me retire. (pause) And that hurt me so bad that I had to retire and quit my job because I loved my job working with boy Scouts. And uh, and uh, I bought a house. And it needed a lot of repair, and uh, we- we moved in that house. And I remodeled that house with one good side. I had one good side. And I would walk around with a cane in one hand and- and remodeled that house. You wouldn't believe- you wouldn't believe the- what it looked like after I got done with it. And uh, we lived there uh- uh- let's see we lived there (pause) five or six years I guess. But anyhow I was sitting on my front porch one day, and there was just like something that spoke to me- like said, "Get up, and get in your car. And go down the road, and hit the biggest tree you can find. And you end it all. You won't ever have no pain no more. You can end it all." And you know I got up and got my hat- and I never did- wouldn't go nowhere without my wife. But that day, after I heard this voice in me, I got in my car, and my wife said, "Where are you going?" I said, "I'm just going around the block." And I went out, and I- I went down the highway, and I turned on a road. And I went to this one crossroad. And I pulled in that crossroad. I could not hold that steering wheel. I could not- I could not guide that steering wheel. And I backed out on the road- back- I went back, right like I came. And I said to myself- I said, "What in the world am I doing?" And I went straight to my sister's house, pulled up in her driveway. She was standing in her door and looking out. And I pulled up and got out. And she said, "Brother, come in here." She said, "I've been praying for you all day." And so I went up and hugged her. She said, "You're going to church with me tonight." And I said, "Well, I guess I will." She said, "You go home and get dressed up, and we'll pick you up and take you to church." And so I went to church. And that night, I got saved. That night, I went to the altar. I got saved. And ever since then, I've been a different creature. Different person, ever since. So that's how- that's how it come. And oh, yeah- I- I took my wife who had cancer, stayed with her after that. And uh, everything just worked out (pause) good, you know. And she was a Christian. My wife was a Christian. She'd been born again.

A: Was- was she a Christian before you turned Christian?

B: Yeah. Yup, she was before I was. Yeah- yeah. A good woman. That's her right there.

A: Yes, she's beautiful.

B: She's got Indian in her. (laughs) You can probably tell that- Indian in her. That's her- that's her when we first got married. And uh, her mother was uh, Indian. And uh, her- her grandpa was full-blooded uh, full-blooded Indian. And uh- uh- he uh- he used to come to our house a lot. And uh, he'd tell us all about Indian, you know Indian stuff. And yeah. (pause) But I've seen- I've seen a good life. I've seen a good life. Had a good wife. I had a good- we lived together forty-four years before she passed away. I had a good life. Enjoyed it.

A: When you um, was holding the steering wheel um, and you couldn't bring yourself to crash into a tree or something, what was going through your mind?

B: I didn't know what was- I didn't know what was happening. I couldn't control that car at all. That car took me right back to my sister's house. It didn't take me back home. It took me to my sister's house. And she was standing in the door with the door open looking out. And- and she said- she- when I got out of the car, she said, "Brother come- come up here and sit. I've been praying for you all day." And she said, "I'm glad to see you." And then she told me- she said, "I want you to go to church with me tonight." So I did. I went to church with her and got saved. And my wife- she was so tickled- and because I'd changed, you know. I wasn't a bad person but I- I'm still a sinner. And uh, so that- that's the way it was. And today I'm happy. (laughs) And I'm happy today.

A: That's incredible.

B: Yeah. (pause) Yeah. All my brothers older than me and all my sisters all were Christians- every one of them. They were all Christians. And I had a brother- two brothers that were preachers and ministers. And- and uh, and every one of them went to church all the time. They- they were good Christian people. And my mother and my father were Christians. And uh, I have a brother- I have a sister still living- two sisters still living, and my youngest three sisters still living. Uh one of them is in the rest home up here. She's nine- today's her- yesterday was her birthday. And I think she'd be- I think she'd be ninety-eight years old. That's old. Ninety-eight years old. And- and I got a sister in Texas- that's my youngest sister. And she's a Christian. And my oldest sister is Christian. But I've got a young- younger brother that I can't say he's a Christian. And that really hurts me. That- only one, you know that's left. And I can't get him to go to church. And that hurts me. He's the one that played music with me in bars and stuff and I can't- I can't change him. I can't get him to go to church. He says, "I'm okay." But uh, that ain't it. You got to prove it. You got to show that you're a Christian. And- and- and that bothers me, you know. To know that one in the family...

A: The only one left.

B: The only one left that- that's not a Christian. And it bothers me. But- but you know the Bible tells us that few that will enter in.



A: Okay. Could you- could you talk about um, what made you a sinner before when you turned Christian?

B: Uh yeah, I- when I was uh, born a- a young person, uh, I- I was in sin, and my older brother bought uh, bought me a guitar. And learned me how to play the guitar. And then I got with the neighbor boys around, and they would drink and have a wild time, you know. And I got to drinking with them. And uh, and I grew up with- with a bunch of boys that was rough- rough. And uh, stuff, and then uh, so uh, that went on I- um- I kept being a sinner uh- uh- out in a sinful world until that time when I made that change, you know.

A: What- what is sin to you?

B: Huh?

A: What is sin to you?

B: What is sin? That's doing wrong. That's- that's uh, well the Bible says uh- uh- adultery uh, fornication which is- which is using another flash, you know going out when you're not married and uh, using women, you know and stuff like that- that's all sin. And drinking and getting drunk and all that stuff- that's sin. And uh, so you have to live a good- a good, clean life. The Bible tells you uh, that's what I live for- right there is that Bible. I read that every night. And I- go- go through read different places in the Bible. And it's a good teacher just like you going to college. And you know, it's a good teacher. I never had a good- good education. And uh, I had to learn by uh, just having good knowledge. And- and I- I went to school for a year to learn a trade. And uh, after I got out of school..

\*Knock at the door

B: Come in.

Woman: Oh I'm sorry.

B: No, that's alright.

Woman: You going to come down when you get done?

B: Um, I'll come down. (door closes) So that- that- that we uh, (pause) uh- that's where- that's where our life is. (pause)

A: That's- that was beautiful. Thank you so much.

B: Okay.

A: Um, so this is it for today. Um, and we'll meet again sometime, and you can choose when. But that's when we talk about your relationships, your intimate friendships, and so on. Um, when would you like to have this?

B: Whenever you want it. You- you say it. I'm in here. (laughs)

A: Okay. Um, let's see maybe uh, next week? Next uh...

B: I'd be honored.

A: Next week at the same time? Next Friday at the same time?

B: Next Friday at one o'clock.

A: Great.

B: Okay.

A: Thank you so much for today. It was a beautiful story.

B: I- I appreciate you.

## **Brain Interview #2**

Participant (B): Ah- good to see you.

Aki (A): You too. You too. How was your week?

B: Uh- doing pretty good.

A: Good.

B: Doing pretty good.

A: Anything happen this week?

B: No. No, everything's pretty quiet.

A: Okay. (Pause) So today is the uh, the last interview. But um, I will be checking in with you um, probably in a couple of months. Like- about like what I thought about the whole thing um, how I analyzed it, and what I found out. And I'll be sharing with you um, everything, um. Okay so, (pause) today we're going to be talking about relationships. And um, let's start by um, me asking you- could you talk about the most important, most intimate relationship or friendship that you had in your life?

B: Uh, with people? Or...

A: Anything.

B: (mumbles) Well uh, I've- I had good relationship with- when I was sit- uh- ranger for the Boy Scouts. Um, (pause) I enjoyed that. And uh, (pause) in the hospitals- when I was in the hospital, I had good relationships with people in the hospitals. A- about everywhere I've been I've always had good relationships with people. I never had- I've never had no trouble with people, you know. And uh- um-

here- when I come in here- same way. Seem like I just fit right in, you know. And uh, I make uh- uh conversations with people. And- and uh, I like to help people. I really like to help people. And uh, (pause) I just- my daughter-in-law just came up a while ago and took me up to the other rest home up at the Knolls and uh, to see my sister up there. She's ninety-seven years old. And uh, I- my friend that I used- we used to- we used to run Beagle- belong to Beagle clubs- and run- uh, Beagles together. And uh- and I- we were real good friends. And I was- he was up there, and they put him up there from the hospital. (clears throat) And he was glad to see- we'd been friends for a long time. And he was glad to see me. And uh...

A: What's his name?

B: Uh, Bill Steepton.

A: Bill Steepton.

B: Bill Sr. And uh- uh, yeah he was- he was really glad. He- he- oh he looked bad- he- bad shape. And he's not as old as I am. He's eighty- I think eighty-one. It- but he's getting up- getting up there, you know. I'm eighty-four- a little older than him, not too much. (pause) But he was so glad to see me. And uh, we- we really had good friendship together, go up and visit with him. And uh- it- it just- it pleases me, you know to see- see some- somebody like that. My- my- we've been friends so long. Did things together- we used to hunt together and- and uh, all that. So I enjoyed that trip.

A: Who would you say is the most important person in your life?

B: Most important was my wife.

A: Your wife?

B: My wife.

A: Let's talk about her.

B: We- we lived uh, together um- we- we got married uh- last of- last of '51. And uh, and we lived together forty-four years. She took cancer. But uh, we had a good friendship- good life together. Raised five children. And uh, we just- just had a good life together. I enjoyed her so much.

A: What was her name?

B: Uh- Ja- Janet.

A: Janet?

B: Janet Faith. Uh- and uh, her mother was Indian uh, and her uh, her dad I don't know really much about her dad because he died when she was- before she was born. And he had Leukemia. (pause) And her grandpa was Indian, and he used to come and visit us uh, but uh, he was real old. And h- his name was Beard- his last name was Beard. And I- I can't remember his first name- what it's called- called,

but uh, we had good friendship. And we- uh- I really thought a lot of him. Um...

A: So you were friends with her family too?

B: Yeah. Yeah. Her family- her mother- her mother was a good mother-in-law. And uh, I had her buried in- in my- my lot. I had her right beside my wife. And uh, (pause) uh, I thought a lot of her, and she thought a lot of me. So uh, we took care of us. And uh, she had a lot of brothers and sisters. I can't remember their- probably six of them. Uh, half-brothers and sisters. And- and she had two brothers- real brothers, and both of them- one died with Leukemia like his dad, and- that oldest one. And then uh, the one that I knew uh, choked to death. He- he- they were feeding him beef, and he choked on the beef. And- and they- they couldn't survive him. And he died- and he was in a rest home. And uh, he died uh, right after my wife was buried. Uh, they went and told him while he was eating that- that my wife died- that was his sister. And it- it excited him, and he had a stroke. And uh, he- he had that beef in his mouth and swallowed and choked. Choked on it. He died. So I lost- I lost my wife, I lost my mother-in-law and my brother-in-law in just...

A: In a short span of time.

B: Right together almost. And uh- but I miss my wife. I miss her.

A: How did you get to know her?

B: Uh, I'm- it- it was a mystery. It- it was something strange. I had a lot of girlfriends that wanted to go with me in my younger days. And I just- I wasn't interested. I used to be- I loved horses. And my horses came first. I- I- I did rodeo and then stuff like that- riding it. And uh, I didn't want to get married. And- and uh, I just uh, I- I didn't uh, really didn't find any girl that I really was interested in. And one day, I was working in a welding shop, and I went to lunch. And when I went to lunch, she was in senior year in sch- high school. And her and her girlfriend came out of a- a grocery store- they went in there and got their- got them a pop and a candy bar uh, from school. And uh, I- as I passed by, I saw her come out of that grocery store. And- (laughs) and uh, I looked at her, and I said, "Boy, there's my wife." And- it- it- it was a miracle. And uh...

A: What- what made you say so?

B: I just- I don't know. I just- I just really liked the looks of her. And- and so that Saturday night- I went home to eat lunch and I thought I'd never see her again. And that Saturday night, I- I'd been in a theater- to see a movie, and I came out, and her and this same girlfriend of hers, were walking down the street behind me. And then I- I heard them laughing, and I turned around, and it was her. And uh, so I stopped, and I said, "Hey." I said uh- I knew the one- I knew her girlfriend- I knew her. And I said uh, "You girls want to go down and have a- a cony dog and a root beer with me?" I said, "I'll buy you a root beer and cony dog." And they said, "That sounds good." So we went in the little restaurant. And we had the- I got them a cony dog apiece and- and a- a root beer. And we sit there and- and chattered. And I asked her for a date. And she- it embarrassed her. And uh, I said- well, I said uh, "You can say yes or no." And- and uh, I said uh, "Would you like to go to the movie with me next Saturday night?" And she said, "Yeah." We met, and we started going together. And we went together a long time before we got married because I wanted her to grow up. She was only sixteen years old. And I wanted her to grow up. I didn't want to marry her right away. And we got married, had five children, (pause) and

lived a good life together.

A: What role- what role did she play in your life? What kind of person was she?

B: Uh- (pause) uh- well, (laughs) I- she was- she was just everything I wanted. She was just everything I wanted. And- and she was a good cook. She was- she was just a good person and a good mother. And she- her children- she took good care of her children. And uh, she- she was a good housekeeper. And just- just everything I wanted in life. And uh, I couldn't have wanted anybody any better. And the girls that- that uh, tried to get dates with me, I watched them all get divorces. They married and got divorces. Her and I never did get no divorce. We stayed together. And- and we- we- we lived- we didn't live uh, rich or anything like that. But we lived good.

A: Did she change you in any way?

B: Uh, (pause) I don't know uh, she- I don't think she tried to change me. I don't think she really tried to change me. And- and uh, she- whatever I said, went, and- was fine with her. Uh, she never did uh, ring a bell I guess, anything that I- I wanted to do. And uh, and I never did anything she wanted to do. She was free to do it. And uh, so we- we uh- we had good times together. Uh, if- if she wanted something, she'd go and get it. (laughs) Uh, and if I wanted something, I went and got it. So we- we- we just played together, you know.

A: Uh huh- played well together.

B: Yeah. And- and it was- (clears throat) I had a lot- (clears throat) I had a lot of sickness in myself a lot of times. I had- I had seizures when I was eighteen years old. And- and she had to put up with that. And she did. She- she took care of me when I was having those seizures. And uh- and she- she- she was just really good to me. And uh, I- I tried to be the same way with her. But uh- uh- back- back in uh- uh, (pause) '69, 1969, I was a ranger for Boy Scouts. And- and uh- one- one day I was in the workshop working, and I had uh- uh- the camp director come in and said, "Hey Brian. Let's- let's go to lunch. It's lunch- it's twelve o'clock. And- and they're having lunch up in the dining hall." Said, "Let's go to lunch." And I said, "Okay." And I walked out. And I got a pain in this shoulder here- a real sharp pain. And went through just like- like somebody shot me a bullet, you know- went through. And uh- and I started to my truck, and he said, "Come on. Where are you going?" I said, "I got to go home. Something's wrong." And so I got to my truck. I tried to get up in my truck, and I had a hard time getting up in there. And I was getting weak. And I thought I got shot. I thought somebody maybe sh- uh- shot me. And uh, I got in my truck and started it up and went over to my house and pulled up in the driveway. And I stopped and got out and went to the door. And she comes to the door and she said, "What's the matter with you?" She said, "You- you look funny." She said, "What's the matter?" I said, "Get me to the hospital." I said, "Something's bad- wrong. I think I've been shot." And she said, "Oh my goodness." And she went out and got in my station wagon, and she went over. And she got the camp director. And uh, she said, "Something bad wrong with Charles, and we got to get him to the hospital." So his wife was a nurse there- at the camp, and he told her. He said, "Call the hospital, and tell them we're on our way." And uh- so they put me in the station wagon, and he comes to the house. And they got me out and laid me and put me in the station wagon. She sat in the middle, and I sat on the outside. And- (pause) and we got here in Oxford coming in the first stoplight. And he- he drove- she- she told me that he drove ninety miles an hour all the way just- just flying, you know to get me there. And uh, with the lights on and- and everything. And when they got to the stoplight, down

flooring it- coming in, she said uh- uh, he had to stop. The light was red. And he honk his- honked the horn down. And she said I just fell over. And she said she told him- said, "He ain't breathing." She said, "He ain't breathing." She said- so he speeded up and got on up to the hospital. And (pause) he come around, and- and she said the nurses was out there with a wheelchair to take me in. And he told- he told- kicked the wheelchair away. He said, "No." He said, "He ain't got time." And he just picked me up. And I was pretty big. And- and he was tall, slim guy. And she said he just picked me right up in his arms and run in the hospital in the intensive care unit. And my family doctor just happened to be coming down the hall. She said, uh- when- when the one woman was calling bl- code blue. And uh, that's- that's emergency. And so he took me and put me on the gurney and said that doctor come- know when- they called that- and he came in the emergency room. My wife said he checked me and told- said, "Get me the paddles." Said, "He's- he's gone." Said, "Get me the paddles." So he used the paddles on me, and the nurse uh- uh- uh- what do you call it?

A: Yeah. What the- tube- or...

B: You know. Blowing in and out. I can't think of the word.

A: Yeah. I can't think of it either uh.

B: And- and anyhow, uh- she- she done that on me, and he done the paddles. And uh, my w- my wife- he run everybody out. And uh, my wife said she had to go out that he wouldn't let her stay in there. But uh, he brought me back. And uh- uh one of the housekeepers there- one of the- one of the uh, hospital cleaners was a friend of mine, and she was there in that room cleaning, and she watched them. And she told me later that uh, it took them about forty-five minutes to get me back uh, normal. And get my- and he got my heart beating again and got me back. And uh, so I stayed- they put me in intensive care. I was in there uh, two weeks- intensive care. They had me on an oxygen tank with uh- they give me oxygen. And uh, but I survived. I survived.

A: Wow. So she was a witness to your suffering.

B: Yeah. And (pause) she was there one night- come to- uh- uh- I was- I was there- they kept me out five days. And I didn't know anything. And then when I come to that- the fifth day- uh- that fifth morning- at ten thirty- she was sitting in my bed. Uh, my wife was. And- and uh- I- she stuck with me. She stuck with me. Same way when I had the stroke in '79. She- she give me therapy and stuff. We- we really- I- I couldn't have found a better wife. I couldn't have found a better person. And uh, we- we was just together real good. But uh- (pause) yeah I- I couldn't- I don't know- I missed her so bad uh, when she took cancer- passed away. But I stuck with her. I stuck with her sixth months. I- I- I sit right beside that bed. And when I had to take her to the hospital, I go in that hospital and stay right there until they let her out. I stayed right with her. And uh, I didn't get much sleep. I- I went down, and I had heart trouble too at that time.

A: How did she pass away again?

B: Cancer.

A: Cancer?

B: Yeah. She- oh cancer eat her up. She had cancer bad. They said it was one of the worst cases they'd ever seen. It just eat her up. And uh...

A: And you stuck with her just as she stuck with you through your suffering?

B: Yeah. Right. Yeah. Yeah I- I stayed right with her- held her hand all that time. And uh, wonderful person- wonderful person.

A: What was it like when she passed away?

B: It was terrible. They kept me doped up. They- I- I- I probably would've died with a heart attack if they hadn't uh. They- but they kept me doped up.

A: With...?

B: With- with pills, you know- with medication. And uh, And I- I went through the- I prayed. I was uh- I- I would talk to the Lord. And I'd pray, "You- you got to help me, you know. You got to help me go through this." And uh- and He did. He helped me, and I made it. But uh, it- it was hard- it was hard to go through that. And uh, I know uh, when she was in a coma- before she passed away, she told- uh- before she went into the coma, she told me- she said, "I want-" Said, "I know I'm going to die." And said- said, "You- you don't live by yourself. You get you another wife, and don't live by yourself." But I could have never gotten me another wife. I could never replace her. And I know there are good women out there, but I couldn't ever. I just couldn't. In- in my- my thoughts of her, I just couldn't.

A: Irre- Irreplaceable?

B: Yeah. (pause) So...

A: What- what is it like now that she's gone?

B: Uh, it's still- still dreadful. It still hurts. And uh, yeah I think about her all the time. I keep her pictures up on the wall here- right up here behind you. And uh- uh- yeah. But uh, I can't do nothing about it, you know. It's just something the good- good Lord done. And uh, every- everybody has to die. So- but uh, I didn't want to see her in that shape no more. And I- I- you know- she's- she's not in pain no more. And uh- oh I- it- it's hard telling how much pain she went through. And uh, yeah.

A: It must have been hard for you.

B: It was hard.

A: Thank you for sharing that.

B: It was hard.

A: What was the most memorable thing about her?

B: Uh, she was always joyful with me. Yeah. She- she uh, eye in the crowd. She was very quiet. She

was very quiet. She- she wasn't one that showed off or anything like that. She was- she had her- her ways- herself. And uh, and uh, but with me, she was always joyful and- and had good spirits. We- we- we uh, really had good times together. And all the hard times we had, we had good times. And uh, got along good. So it- it was- it was something. Uh, I could write a book on- (laughs) on my wife, my married life. It- it was just wonderful. And uh, my children- we raised uh, five children. And all them grew up real good. They- they- they- they uh, minded good. They- they were good kids. They didn't get in no trouble. And then when they- course when they got old enough to get out, I- I could- I can't control their life then. And (pause) my oldest boy- he- he got into drugs. And uh, he- he got with some girl, and she got him on drugs and uh, ruined his life. And uh, and then finally he uh, year- two or three years ago, he had a motorcycle wreck and died and got killed. But uh, the boy that I got that- that I lived with, Rick, (pause) he took good care of me. And my youngest boy was good to me. Uh, my girls were good to me. I had two girls. And uh, both of them was real good. And uh, they're- they're all out to themselves. They got their own homes and everything and doing good, you know. But uh, my oldest boy just got into bad when he- when he got the wrong girl. He let- he let a girl take him, you know. And uh, she got him on drugs. And I couldn't get him off of them. I tried my best all- all the years. I tried my best to get him off of them, and I couldn't get him off of them. And finally, his liver got bad. And uh, when his liver got bad, they told him he had to have a liver transplant. And he- he- uh- uh- course he couldn't work. They- they wouldn't let him work no more. He was sick. And he couldn't afford no liver transplant. And so he- he uh, used those drugs for medicine. And uh- uh- it- it was just terrible. I tried every way I could to help him, and- and he wouldn't take my help. He- he just wouldn't do it. He was embarrassed on the way he done, you know. (pause) And uh, but he quit the drugs before he had that motorcycle wreck. He quit the drugs and quit drinking- quit alcohol. And uh, but he was selling the drugs. He got to selling them. And that's bad. That's just as bad as taking them, you know- gi- uh- giving other- other people drugs. So uh, he was- he was selling them to live. He over- make a living. And uh, to pay his doctor bills and things. But uh- uh- yeah I had to lose him. And- and uh, (pause) there was- there was just nothing I could do about it. But uh...

A: You miss him?

B: So I miss him. Yeah.

A: (pause) Thank you- thank you for sharing this. Uh okay- um- remember last time you talked about the time that- um you were sitting on a porch, and- um you were retired from your...

B: Stroke.

A: Right. And um- and you were feeling very sad- um- and some voice told you to uh, go drive your car and hit into a tree.

B: Right.

A: Um, before that moment, I'm wondering what your relationship with your wife was like.

B: Uh, with my wife? My wife- we had good relationship- real good. And she worried- she worried about me. I had the stroke. She give me therapy and help me all the time I had that stroke and- and really brought me out more than what the doctors and things did. She done more uh, for me. Uh- because- uh- uh- she knowed how to handle me. And uh- uh- uh- when uh- when I went to get in my



car, I went in to get- and put my cap on. And I never did go anywhere after I had that stroke. But what she was and sitting in that- uh- passenger's side in my car with me. She was always with me and never let me go nowhere without her. Well that day, whenever uh- whenever that- I- that voice spoke to me and told me to do that, and I got up and got my cap, she knowed something was wrong. And she said, "Where you going?" And I- I lied to her. I told her- I said, "I'm just going around the block." I said, "I- I'm just going- you just don't worry about me. I'll be alright."

A: What made you- what made you say that?

B: I don't know. I don't know. I didn't want her to worry about me I guess. And I go- I went out and got in my car and took off. But there was something- had to be the good Lord- that- that had His hands on me because uh- I- I never hit no tree. And I got to that crossroad- pulled in there, and that car backed out. And I to this day I can't tell you what made me- me- that- I- I couldn't control that car. I couldn't tell you. And I- and I- ri- ride back like I came and went to my sister's house. She was a good Christian woman. And she said- she was standing in the door with the storm door open, (clears throat) looking out. And I pulled up in her driveway. And she said uh, "Get out Brian, and come in here." She said, "I've been praying for you all day." And so I got out and went up to her and hugged her neck. And she uh- she said, "You go to church with me tonight." She said, "I want you to go to church with me." So I said, "Okay." She said, "You go home and get dressed." And said, "We'll pick you up and take you to church." So I did. I went home. And my wife- I told my wife I was going to church. I said, "Get ready." I said, "You go." She said, "No. I won't leave the- I won't leave the two boys here by themselves." And- because we had some bad neighbors. And she said- uh, "I won't leave them by themselves." Said, "You go- go ahead and go to church." And uh, my wife was a good Christian too. She was already a good Christian. And so I went to church. And that- that night I got saved. And uh- and I was a different person. I've been a different person ever since. Ever since that day I've been a different person. And uh- yeah I- (pause) that's what makes me- that's what makes me go out here and associate with these poor people out here- it's bad awful. And try to help them, you know. I try to- to talk to them. And...

A: You said you became a different person- the way you looked at your wife- did that change?

B: (pause) Yeah.

A: How so?

B: It- it- you mean...

A: After that day whe- whe- when you- when Chri- Christ found you...

B: Just- just made me love her that much more.

A: That much more?

B: Yes, that much more. (pause) Yeah. My wife- my wife was just- she was just a part of me- that's all it was. She was just part of me. And she cared for me just like I cared for her. And uh- and when I- when I come back from church I told her I got saved. And she just- oh she grabbed me and hugged me, you know. And said, "I'm glad. I'm glad."

A: Did you tell her everything?

B: Yup. Told her everything. Yup. And...

A: What did she say?

B: So- she- she just said, "I'm glad. I'm glad." And uh- yeah- we- we- I- I don't know uh- my mom and dad were- were just about the same way uh, in their life. They thought so much of one another. And uh, they- my mother was a good mother. You know she raised fifteen children- she had to be a good mother. And uh- and she- she took care of my dad- my dad- my dad worshipped over her. Everything she done he- he'd worshipped her. But uh, they lived together- goodness- uh- uh- fifty- sixty something years I guess before they passed away. (pause) Yeah- yeah it's something, you know. But I had a good family. And uh, and all of my brothers and sisters uh- the fifteen of them were all good people. And uh, all of them's gone now. But- I've got uh- I've got uh- three sisters left and one brother.

A: So five of you? Um, now you had a couple of um, strokes um, since that day um, and we talked about thinking about death a lot, but I'm wondering how those thoughts about death affected your relationship with your wife. Could you talk about that?

B: Uh- with her death? Or with...

A: With- with your own awareness of...

B: My awareness. Uh, (clears throat) I don't think it affected us any. I don't think it- it- it- uh- I think it put us more closer.

A: Closer?

B: Closer to one another. Uh- uh- because- uh- uh- she was always right there with me uh, all the time. And she just- she worked so hard to get me well, you know- to try to get me back- uh- and- uh- going. And when they retired me- when they retired me from my job, they wouldn't let me work no more. And the doctor told them I had to retire. And uh, I- I really got mad. Uh- I got mad 'cause I didn't want to retire. And uh, my wife- she said, "We'll make it." She said "Honey, we'll make it." Said, "Don't worry about it. We'll make it." And- so she helped me- she comforted me uh, through that. And uh, I- I bought a- I bought a place, and we moved. And uh- uh- I remodeled the house and everything. She- she was right there- right with me all the time. And uh- (pause) and when I- you- you know when you have a stroke uh, there's times that you just break down and cry. And- and you don't know what to do. Uh, you're helpless. But she- she was always there to comfort me. And she put her arms around me, and she said, "Charles, just go on now and straighten up." And said, "We'll make it." Said, "You can make it. You come back." And- and it lifted me up. And I- I- I'd get back up and go back to work- uh- working on the house, you know. And uh- so- it- it- that's why that I miss her so much. Because uh, she was always there. (pause)

A: She was always there?

B: Always there. (pause) Yeah. I've got all five of those children. But uh, I guess- I guess they- they worry about me. I don't know, you know. They- they- they- but they've got theirselves. And I- I'm one of

them kind that don't want to put my troubles over on anybody. And uh, they- they tell me that's bad- you shouldn't be that way. But I don't want- I don't want to put my troubles over on my children. And I don't tell them a lot of the times when I'm bad- when I- I get bad down sick. Uh, I keep it hid from them. And uh- uh- (pause) but uh- yeah- life is uh- sometimes worries me, but (laughs) we make it. We make it.

A: Like your wife said to you?

B: Yeah.

A: Make it together with her.

B: Make it together- yeah.

A: (pause) Thank you so much for sharing about this.

B: Yeah.

A: Would you like a tissue? Um...

B: I got one here. Thank you. Yeah- it- (pause) life is so much different since I- I got the Lord in my life. (pause) And I changed- I depend on God helping me. (pause) And they know that. My children know that. And they- here they know that. You can go out and ask any of them. They'll probably tell you what kind of life I lived in here. And uh- but I- I'm one that I like to help everybody else. I- I've lived my life- I'm eighty-four years old, and- and- uh- I can't- I can't do anything more for me. So er- eh- I- I try to help everybody else. I try to pick them up. And there's people out there that don't even know what day it is. They don't know uh- you can tell them what day it is, and they'll turn right around and ask you what day it is. They don't know. And I go up to them, and I talk to them and have a conversation with them and uh- tell them I love them. And big smile will come on their face. That makes me happy. That makes me happy. If I can help somebody else, it makes me- it makes me happy. But uh, that's all I can do anymore. Uh, my legs are bad, and uh- I- I- it's hard to get around. And uh, I'd loved to get out. I know they have a program here- the- the uh- uh- uh- the people that- that- that uh- oh I can't think of what I want to say. (pause) Uh, that they- they uh- will take you outside and- and- and let you do anything, you know. Uh, they help you like pulling weeds out of the flowers or something like that, you know. And uh, and they- they uh- they're so good to me. And uh, just like when you come in- out there- I was tell the lady and- and- uh- I said, "I fed the squirrel last night- out there." And I said, "It wanted a drink. That it was drinking out of that old tobacco tubes." (laughs) It was sitting there. And I said, "It- I hope it comes back tonight." And- but I said, "It maybe drunk on that stuff, you know." And uh, so she went out and emptied that thing. And was helping me out- activities lady- that's who she is- she's the activities lady. And uh, so I said, "We're going to have to get something to put water out there, so he can have some clean water to drink." (laughs) And I'm hoping tonight- it comes every night, and uh- uh- at- this couple a women that comes, and I take them up there to the window and show them that squirrel. And uh, we sat there and- and watch it eat. And the little old thing it eats until it gets so full- it can't eat no more. And then it goes over and tries to drink out of that old tube of tobacco- uh- thing and- where they put their cigarette stubs in. And uh, so I told her- I said, "I don't want that squirrel drinking it." And so she emptied that out. And she was fixing that for me. (laughs)

A: You were doing something nice to the squirrel too.

B: Yeah. I- so she said, "It's going to rain directly, and it will get some clean water." I said, "It may not rain. We haven't had no rain." And I said, "It may not rain. That squirrel's got to have some water." (laughs) And so I got this can, and I- I- I- I had nuts in that can. Well I put the nuts in here, and I'm going to feed it them nuts. And uh, I fill that can up full of water. I'll- I'll take it out there and set it down, so it can have some water.

A: Were you always nice to animals? Or is this something recent?

B: Animals?

A: Right- like squirrels.

B: Oh I love animals. I love- I love that animal. Yeah I- I- I've always- all my life- all my life I- I've loved animals. I'll show you something...(pause) That's me when I was a little, bitty boy. Look at what I've got in my lap.

A: Looks like you've got two puppies, huh? Wow, this is so cute. Who is this?

B: I- I don't know. (laughs) I don't know who that is. That's probably one of my brothers. That's probably one of my brothers looking through the fence at me.

A: Were- were these your pets?

B: Yeah- uh- and those- those little puppies- I had those little puppies. That's me when I was little. (laughs) And my son found the little picture in my pictures. And he made this big one for me off the computer. And uh, brought it in to me. And uh, yeah- it's uh- it's something, eh. They took uh- they took these pictures here at- at the rest home. They had the 4-H club come in with animals, and you see me holding that sheep? (laughs)

A: Oh yeah. (laughs) Oh wow. Who- whose sheep is this?

B: Uh, the activities lady took that picture of- we- we had- had that there. And they- they take pictures of me about everywhere I'm at. (laughs)

A: That's wonderful. It looks- you look so happy in this picture.

B: Yeah. (pause)

A: Wow. You enjoy having animals around you.

B: I do- yeah. (pause) Yeah, that little squirrel out there- uh- I was so proud of that little squirrel. And uh, (pause) this is my wife here holding one of the little grandchildren from in the hospital.

A: Uh-huh. What was the grandchild's name?

B: She- uh- I don't know which one that is. Um, I don't know. Um- that- that's- I think that's my little

granddaughter, Emily. But uh- I'm- I'm not real sure, but I think that's when she went to the hospital when she was born. And uh, that's probably her. Uh- (pause) so- yeah- this- this is my two little granddaughters here. And this one here is blind. Uh, she was born- she weighed a pound and three quarters. She- she was down- uh- born early. And uh- and she's going to college- uh- at Rice State College. And- and she's already put in two years. And I don't know if she's going- uh- uh- this year or not. I don't know. I haven't heard. Uh- but uh- they- they taught her computer. She does computer work. And- oh she's smart. She's real smart. Edu- education- good education. And that's her sister. And uh, she's- she's wo- got a job at a factory up in Eaton now. And working in a factory- she's got beautician license- she was a beautician. But uh, she quit that and went to the factory for some reason- make more money I guess. I don't know. But uh, (pause) yeah...

A: Thank you. Um, I have one last question. Um, you- you said um, you're legs aren't moving so fine um, and that like helping others- helping uh- even like animals um, that's all you can do right now. Uh, could you talk more about that? What- what did you mean by that's all you can do?

B: Well- it's- I- I don't have the health, you know, to get out and work. Do a- do a man's job, you know. And that hurts. That hurts me 'cause I worked hard all my life. And I like to get out and- and do things. I even asked- I even asked our maintenance guy here- I said, "You give me some tools, and I'll help you." (laughs) And- and he looked at me and, "We'll see." (laughs) But uh- if- if I do a little bit of hard work, I have those spells. And uh- and uh- they don't want me having them spells. And- and they're bad. And uh, so- yeah- it's- it's- it's ro- rough to get a little old, you know, and everything where you can't do what you want to do. But God has always took care of me. And uh, I rely on Him a lot. Like I was telling my friend- I just went up and visited the other rest home. We were- we were close friends together. And he said- he said, "Brian, you've always been one that- that was really hang in there and- and wouldn't give up." And he said, "You know..." He said, "Here I am laying here." He said, "I just about to give up." He said, "I just seem to go on." And I said, "Well," I said, "It- it might be nice to go on." But I said, "We got something to live for. We still got something to live for." And we don't know what we can do to help somebody. And uh, why- why would we want to die, you know. Uh- when- if- if you can help somebody. And uh, I- I- I want to live as long as I can. And uh- and you know God suffered. Uh, the Lord- He- He suffered. His own people uh- treated him bad, and He suffered. And uh, when I read that Bible there, it tells me how He suffered. So I feel like long suffering ain't going to hurt me as long as I'm with him. And uh- uh as long as I believe in Him, uh- I'm- I'm alright. So- (pause) yeah it- life is what you make it. It's what you make it. So...

A: So you made suffering meaningful by helping others?

B: Right. Right. What- what you can't do- but you can help somebody else, and it'll pick you up. It'll- it'll- I don't know it makes you feel good. I feel good helping somebody. And if I can go out there and get a smile out of somebody, that- that makes me feel real good. So (pause) that's what I live for. This- this little, old room is all I got here that I live in.

A: To think of all the wonderful things that you're doing in this room- to other people.

B: Yeah- right. Yeah, I don't worry about a thing that I got back home- back at my boy's house. I don't worry about a thing back there. Whatever he does with my stuff- that's- that's o- I don't every worry about it. 'Cause I ain't going to never get out of here to enjoy any of it. And uh- probably couldn't enjoy it anyway. (pause) So I just- I just live day by day. And when I can do for somebody in here- that-

that'll make my life- rest of my days. And uh- yeah- yeah- any- anything that I can help someone else do. That's like my buddy when I went up there and visited him long ago. He said, "Boy," he said, "We've always been friends, Brian." He said, "You've always helped me. You just- you've always helped me- lifted me up." And I said, "Well, Bill, that's what friends suppose to be. That's what we're suppose to do. We're suppose to be that way." And- so- I- I remember when we go to the club- uh- to run our beagle hounds, and we'd lose, uh- I'd just laugh about it. And he'd get real mad, and I- I'd pat him on the shoulder and say, "Oh, come on." He said- I said, "We'll go make some- we'll get them dogs better next time." (laughs) And- and he's talking about that up there today. But uh, yeah...

### **Tammy Interview #1**

**Aki:** Could you talk about what life is like right now in a very general way?

**Participant:** Ok, my life right now?

**A:** Yes

**P:** Um, well I retired a year ago and so I am really having a wonderful time with it. I do some volunteer work so I get out and I'm around people. But I also have a lot more time to pursue things that I'm interested in. I tend to be a bit of an introvert so having more me time has been really good for me.

**A:** Uh huh. What kind of things are you getting into?

**P:** A lot of the volunteer work is- I'm volunteering at the Community Choice Pantry and I also volunteer at the Family Resource Center and sometimes there's overlap between some of the clients in both places. And it just feels good to be able to contribute and help people. And then I do needle work and I've been able to spend a little more time doing yard work. I also sing in the church choir and I've been a little more involved in some church activities.

**A:** Sounds like those activities are very fun.

**P:** Yea, I've been attending, taking part in the prayer group and then once a month the women from the church have lunch together so I've been able to start doing that.

**A:** Very nice.

**P:** I am at a very happy place in my life right now.

**A:** I'm very happy to hear that. How do you see your future from here? Do you have any plans?

**P:** A lot of right now is, because I still have a son in college, he's finishing up his senior year. Short term it's mostly supporting him through that, getting through college and then his decisions for what he's going to do in the future. I have pretty much planned to stay here and probably in this house as long as I'm physically able to do so. Although, you know, as Kyle is getting older I'm starting to think that, you know, if his future takes him outside of Oxford that there may come a time when I would relocate. A lot of people that I know, through church mostly have gotten to the points in their lives where they aren't able to live independently and are relocating to- not necessarily live with their children but to live closer to a child so that it's easier for the family relationship and the family support

to continue.

**A:** Uh huh. You want that connection.

**P:** Right. So and he's my only child. So I am starting to think that, you know, sometime it might be 25-30 years from now I may relocate because of something like that. I used to tease my youngest sister is ten years younger than I am. I used to tease, since she was the youngest I was gonna move up to where she was and she'd have to take care of me when I got old.

**A:** Oh wow. Where does she live?

**P:** She's in Columbus.

**A:** Uh huh. Do you have any plans or projections as to what kind of life you want to be living for the rest of your life?

**P:** I would like to be able to be independent and to be able to live on my own as long as possible. I really don't like the thought of having to be in a nursing home setting. I know that facilities are certainly improving and care has improved over the years but I don't know. To me, that is probably the thing that gives me the most discomfort is the thought of having to be long term in a nursing facility.

**A:** What about the nursing facility gives you discomfort?

**P:** Um, I guess, you know if I had a private room it probably wouldn't be that bad. It would be having to share a room with somebody else and feeling, I think feeling like I had to be on my best behavior all the time because somebody else was there or something like that.

**A:** That being watched.

**P:** Yea, yea. And the feeling, I think I would feel like I was a guest in somebody else's home type thing. Home isn't the right word. I mean because, this is my home and I can do what I want and whatever schedule that I want but I guess I feel like if I were in a nursing facility, its not my home and I would feel not- like I didn't completely fit in because its not my place.

**A:** Is it the sense that you want to be the owner of the home that you are at or is it something different?

**P:** Um, I don't know that its ownership as much as sense of belonging.

**A:** Ok. So even if it's a group, a communal type of place, if there is a sense of belonging then that would make it better?

**P:** That might help but I'm also, I think I mentioned I tend to be pretty much an introvert and to have to be in a group situation is- I'm not comfortable in large groups of people.

**A:** Does the fact that it's the last stage of your life affect your preference?

**P:** Um, no that would not be the last stage of life because my preference now is pretty much to- I have

been on my own since 1993 and it's just been myself and my son most of the time. So I'm very comfortable and mostly by myself getting out and interacting with people a little bit but being able to come home (Aki: being by yourself) and being by myself. Sort of recover from.

A: So all the social interaction, is it tiring to you or how do you make of it?

P: Um, I always have the dread of going to something, to a social thing. Going to a volunteer activity doesn't bother me because I have a role there. I know what I'm going to do and it's not like a social function like where I'm not as comfortable with the social interaction with a large group of people. I'm very good when I'm with a small group of people that I know well.

A: Mm hm. That sense of belonging is there.

P: Yea and being able to relax and be comfortable. Not on stage.

A: Uh huh. No performance anxiety. Ok. Could you talk about what death is going to be like for you? How it's going to happen, how do you feel about it?

P: Um, I was with somebody once and we were talking and I can't remember ever being afraid of being dead. Death itself not really scared me. The process of dying is a different thing. And it was funny because this other woman felt exactly the opposite. She wasn't worried about the process of dying but she couldn't handle the concept of no longer being alive, no longer being in the world. And for me, I would love to just fall asleep and not wake up and never feel any pain or discomfort. And that would be a beautiful thing. It's a beautiful way to go. I think I've always kind of felt that knowing that life didn't, this physical life didn't go on forever made it more precious. That you should try to appreciate and enjoy it and make the most of it because it wasn't going to last forever. I grew up Roman Catholic and I'm now in the Episcopal Church so I'm pretty sure that the idea that there is a life after death has probably made that easier for me. The idea that yes my physical body will end but something will continue. And it's that something that might continue that has been an interesting transformation to think about.

A: Huh. Could you talk about that transformation?

P: I think that the really interesting things are my son is, he's majoring, his second major is comparative religion and he's taken some classes because his international studies major has a focus on Asia. He's taken a course on Asian religions and he's currently taking a Buddhism class. So we've been talking about the concept of the soul and different religious experiences. It's that transformation and learning about how other people think about the soul. And then recently I heard somebody on MPR, he was a neuroscientist talking about mind and talking about how the mind comes out of the brain and they can do brain scans and you can tell when people are thinking or when they're feeling emotions and stuff and talking about that mind-body-spirit thing and the mind coming out of the brain, it's not the brain, it's not in the brain but you have to have the brain for the mind. I'm going oh- that's an interesting concept and so when you die and the brain is going to decay along with the rest of the body so what does that mean about the mind. If I believe I have a soul that continues on, what happens with that mind thing especially in the context of learning about some religions where your soul is a unique individual soul to you so that when you die and your soul continues, that's you, the essence of you. In other religions that soul gets absorbed back. That soul has always been God and gets absorbed back,



that you don't have an individual soul. And so that has been a new thought for me as to what that means for afterlife.

**A:** What are the theories that you have?

**P:** I used to have the idea of- of course I was raised with the individual soul idea. And then when I was thinking about this brain-mind thing I was thinking about how in the tradition that I was raised in there's the belief in the resurrection of the body. At the end of all time that your body will be brought back. I thought, well if you're going to believe in an individual me continuing to exist as the individual that I am now, you would have to believe in the resurrection of the body. But, um, there's also a part of me that thinks it really doesn't matter (laughs) because when I'm dead, you know, if heaven is true, if an afterlife is true, if my body is resurrected is true, well that's wonderful. But if its not, it doesn't matter. So I'm kind of like, at this point I'm not sure. I mean I would never try to tell anybody, I would never have before told anybody I have the only right answer. But now I don't even know what my answer is right now.

**A:** Ok. So does having the right answer matter to you right now?

**P:** No. It doesn't. And I do tend to believe that something continues.

**A:** Ok.

**P:** And whether its going to be me as an individual or whether I become one with God and cease to exist as an individual, to me that's fine to have something. That does not bother me.

**A:** So when you hear, when you watch something on T.V. about neuroscientists finding out about the connection between the mind and the body and the soul, does it trouble you?

**P:** It interests me. It doesn't trouble me but I think its, it makes me think. It makes me stop to think but it doesn't cause me to stress.

**A:** Uh huh. So it sounds like in different stages of your life you had different beliefs and it changed over the years. Do you think you became- how did your fear level if you will, or how did your feelings about death change over the years?

**P:** I think because I've always pretty much, I mean I still have that tendency to believe that my soul will continue on. So I don't think that I've had a fear level about death. Its more an intellectual change than an emotional change that I would say. I mean nobody likes the thought of dying and certainly, you know if, if you get into a situation where it's dangerous of course I'm going to react at that time. But to sit and think about it, I'm certainly more distressed at the thought of my child's death. That, there I'm getting choked up already. That would disturb me but my own does not except for the concern for those that are left behind. I lost a brother eight years ago and he died very suddenly and unexpectedly, a heart attack and um, the most difficult part of that experience was watching my parents go through it. And so for me, that is the only distressing thing about dying would be knowing that the people that would be left behind would be suffering.

A: That others would suffer for you.

P: Yea.

A: How are you feeling?

P: I'm fine.

(Pause)

A: So it's not really about the just distress you feel about your own death but thinking about how others would deal.

P: Right. Because my first thought after watching my parents go through my brother's funeral and burial was I cannot put them through that again. No matter what I do I've got to at least outlive my parents now.

A: How did they deal with that?

P: It was, um, it was a very difficult time for them. They have each other. My mother is more of a talker than my father. But they have community. They have family and friends and a lot of my siblings are still in the same town where my parents are. So they were able to be there and support them. Actually, my brother died at the end of May and in August I have a sister who was working in cardiac rehab and she said there is a heart walk in August. Why don't we as a family take part in this? And we did. And it was all of my brothers and sisters and my brother's widow came up from Tennessee with her children and it was extended family. And we all got together and we all raised money for the heart association and we all did the walk together. So I think that was a very important thing that we did.

A: You were together.

P: We were together, we took part in an activity together, it was a positive activity. My father had had several heart attacks and bypass surgery and stuff so he was honored at the walk as a survivor as well as were honoring my brother, his memory. So to come together as a family to do something positive, certainly there are a lot of things that have come out of the research work that has been done in cardiac care that my father has benefited from over the many years that he has dealt with his heart disease. You know, to feel that you are contributing; I think was a very positive thing for the family.

A: Does that say something about how hard the negatives were?

P: Of my brother's death?

A: Right.

P: Um, well he was only 49. He was, I was the oldest and he was the oldest boy. And he was named for my father. So I think a lot of that, you know parents never expect to outlive children. So that was very hard and I think the total unexpectedness of it made it difficult too. There was no, there was no opportunity to prepare for it or to say goodbye or anything. Although, I worked with a woman once

who lost five family members over the course of two years. Some were older than she, some her age, some younger. Some sudden and unexpected, some long and drawn out. And she said to me, she said “I don’t know what to tell you. There’s no easy way to lose a family member.” So..

A: And you resonate with that.

P: Absolutely, yea. You know, you always cry.

A: It affects you to this day.

P: Yea. Its, sometimes I will tear up and sometimes I won’t. It all kind of depends. We had a funeral with extended family a couple weeks ago and it was my sister-in-laws sister and she was my age. She was the oldest child in her family and her mother, her father had passed away and her mother was still alive. So because we had a nephew and a niece in common and we all, both sides of the family would often be together for things like birthdays and graduations and holidays so we knew each other. And it was very much like every time we talked to one of this woman’s brothers or sisters they would say “you know what we’re going through because you’ve been through it” and my sister and I would just lose it and we’d start crying right then.

A: Now I understand why you said that I’m lucky that I got to say goodbye to my grandfather.

P: Yup. Yes. Because I, we didn’t get that chance.

A: I’m very sorry then.

P: But he also, because he went so suddenly, there was no pain. There was no, he had a massive heart attack and from what I understand he was probably gone before he hit the floor so there is knowing that he did not suffer. And knowing that we had a very good relationship and I have no regrets. I mean there’s nothing that I wish I had a chance to tell him this or I wish I had a chance to apologize for something that I’d said. Because I never, I mean we had such a good relationship there was nothing to regret that I didn’t have a chance to explain why I said that or why I did that. So you know, there were those aspects that were comforting but he left a wife, he left 3 children, his parents, you know, were not expecting this. Those were the difficult things. So you know, there are things on both sides.

A: The unexpectedness of it brought some positives but it was also hard for many reasons too.

P: On the other hand, when my grandmother was 101 years old and she died I still cried at her funeral so I mean we certainly, that certainly was not a totally unexpected thing and she had lived a long life and the last two years she’d been in a nursing home. So you know it was not, it was not, she had had a life, she lived it fully, she was no longer as able to be involved in the world but still I cried.

A: It affected you nevertheless.

P: Yes. Yes.

A: What do you think will happen when you die? P: I’m not sure how you mean.

**A:** Sure.

**P:** Are you talking about what everybody else will do? What's gonna happen?

**A:** Yea, everything. We talked a little bit about what you think happens metaphysically. What happens to your survivors and what are the things that you think about when you think about your own passing away?

**P:** Well I do have a will. And at this point I've got my brother, my second brother is the one who is going to be in charge of taking care of things like funeral arrangements and what happens with all my earthly possessions. Kyle is 21, legally he's an adult but emotionally no, I can't dump that on him yet. He's 21, legally an adult but still I don't think he would be and we've talked about it and he said no I don't want that responsibility at this point. There will be a memorial service, I want to be cremated. My feeling is I do want Kyle to have some say in what will happen with the cremains. There is an option for me to be buried-there's a memorial garden in our church. But if I were to die when Kyle is off in some other part of the country and he would like to have my ashes closer to where he is, if he wanted to visit the site where I was buried. I'm very much, I don't much care what happens once I'm dead but I do want to be cremated. I do want to make as little impact on the earth. I don't think they, thinking environmentally as well as ecologically as well as other ways. I do have some written down, like things for a memorial service- what readings I would like. What song, hymns I would like. That kind of thing.

**A:** Could you talk about those selections if you don't mind?

**P:** Yea. I don't have, its been awhile since I've looked at them but I do know there is a, in Handel's Messiah, right after the hallelujah chorus you get the big rousing hallelujah chorus and after that, I'm a soprano so there's a soprano solo that comes after it and she sings "I know that my redeemer liveth. And the world destroys this body yet in my flesh shall I see God." And to me that is such an amazing to have that single voice after that big chorus. That single voice with that very personal statement of faith. So that actually comes from I believe it's from Job. So that is one of the selections that I have. And then one of the hymns has to do with, its Lord of All Gentleness, Lord of All. I forget but it talks about all the various stages of the day. Be there, be with me morning, be there in the afternoon and there's one talking about his hands skilled at the tools of the carpentry trade and be with me at the end of the working day and at the very end be with me at the close of the day. So I kind of like the idea of thinking about how God has been present in your life at the morning, at the afternoon, at the evening and at the close. Of those various stages of your life and that being reflected in the stages of the day. So that's one of the hymns that I chose.

**A:** Ok. And going back to this assumption of thinking about the others who are going through when you pass away, what are you, well first who are you most concerned about and what are you concerned with him or her thinking or dealing with?

**P:** Of course my primary concern is my son. His father died seven years ago now, they were estranged at the time of his father's death. And they had not been close for awhile. But I do worry about him and I am the only parent he has right now. He doesn't have any brothers and sisters. He's got a half brother and a half sister who are much older. They're the same age as some of my brothers and sisters. His father was 16 years older than I was and they've not been close, they've not lived in the same town. My brothers and sisters, his aunts and uncles and his cousins don't live here in the same town. So he gets to

see them pretty often and I think he's pretty close with some of his cousins, but he's going to be pretty much on his own when I pass away. He's been through, he's lost grandparents, his father's mother, his father, his uncle. So he's been through the experience. I know he doesn't have the same faith beliefs that I do. I know he believes in God but I don't really know how much of a comfort, a religious ceremony or faith will be for him so that's a concern about where he will find the support. I know he's got friends, he's got some family support. So that's a concern. I already talked about not wanting to put my parents through losing another child because that was very difficult for them.

**A:** You don't want it to happen to them again.

**P:** Right. I think because I'm the oldest of my brothers and sisters that, I think that was probably one of the hard things for me. I thought that I'm the oldest that I should've been the first. And so I don't think it will be as traumatic as my brother's death for my brothers and sisters.

**A:** What do you worry will happen to your parents when you do pass away, if you do pass away before them?

**P:** They're both starting to get, they're both over 80 now, they're starting to get a little more fragile. I just worry that it would, the emotional distress would be a lot more physically a problem for them. I know my mother lost quite a bit of weight after my brother died. And you know, and that was eight years ago. You know my father, with his heart condition, he's had quite a few stents but the last time that he had the angiogram done there was a blockage that they said we can't do anything about. So he's always been, it's always been every time he has an event and they have to call the life squad and he goes to the hospital we're always like it could happen anytime. So I guess I worry that with his health being sort of, I worry about their physical as well as their emotional distress. More the emotional but like I said their ages and they're starting to become more fragile.

**A:** Uh huh. I want to just ask this. Are you more worried about how others will respond to your death rather than what happens to you when you die? Does that make sense?

**P:** Yes. That really is, because when I die, you know if I'm right and there's an afterlife, I will be fine. It's like when my brother died and I said I know that we aren't crying for him because of our faith-Christian faith. We believe that he is with God. So I'm not crying for him, I'm crying for us. And so you know, I do believe that somehow or other my soul will continue. I will be either in the presence of God or one with God. You can't beat either of those options as far as I'm concerned. And like I said if I'm wrong, and I'm gone, it's not gonna bother me. I mean, when you're dead, if all there is when you're dead is nothing, it's not going to affect me. And I can accept that. So yea it's more of a distress to me what happens to other people.

**A:** Because it did sound like, when we were talking about what happens to you it was very intellectual, but it did get more emotional as we talked about what happened to others.

**P:** Yea, yea. Well I guess I do have faith, like I said if I'm with God or part of God-get absorbed back-either way that's good. So I don't have fear of what will happen to me as an individual after death.

**A:** The faith is very strong.

**P:** Yea. Now I don't know what form that afterlife will take. And if I'm wrong, oh well I can't do anything about it. That's kind of the way I am about it. To me, being dead is not a problem. The fact, I mean I'm alive now, and knowing that I will die someday is making this life precious.

**A:** What are your concerns, you mentioned before that it's more about the process of dying that is scary or something. Could you elaborate on that?

**P:** I don't want to be in pain. I don't want to be in distress. I don't want to be struggling and gasping for breath and I just don't- the physical discomfort, the physical pain is what I don't want to have to experience. I don't know that, I think if I were told that I were terminally ill with cancer- with Kyle now being older and able to take of himself and I were told that there was no way they could prolong my life even by just a few months with chemotherapy and having to go through all that, I think I would say no I just want palliative care. Now when he was very young I would've said do whatever you can so that I can be with him as long as possible to help prepare him to lead his future life. But you know right now we're kind of like at that, if something happened to me I'm pretty confident he could manage on his own and he will be ok but it sure would be a heck of a lot easier for him if it didn't happen for another 10-20 years.

**A:** Is there, I might be off on this, the sense of not wanting to be somewhere that you don't belong. If you are getting treatments for that, the likelihood that it might be that you would be in a place, maybe in a hospital or a hospice. Does that factor into that do you think?

**P:** Hm. Not really. I mean, I guess its just that I can't see going to great extremes to prolong a life for a few months when that life is so miserable that I'm not feeling like I'm contributing to something in some way. I think its more that.

**A:** Contributing to something.

**P:** Yea. If I can't interact with other people. I mean I know that at some point I'm not going to be able to go down the street to the Choice Pantry and help people pick out food or work at the computer. That at some point what I contribute, as my physical abilities diminish my circle of what I'm able to do. But I do think that as long as I'm able to interact with people that you do have something to contribute. I mean even if its just listening to my child talk to me about what he's going through and helping him sort out his ideas just by being there to listen and respond. To me that's being able to contribute some way. But if the care that is keeping me alive is not allowing me to even do that much, I just don't see the point in continuing to prolong a life that doesn't have some purpose, some contribution.

**A:** So the interaction is meaningful.

**P:** Mmhm.

**A:** Ok. That's pretty much it for my questions. Is there anything that you want to talk about death before we end?

**P:** No I don't think so. I talked a lot didn't I?

**A:** No this was great. Thank you so much.

**P:** Oh you're welcome.

**A:** Are you feeling ok?

**P:** Oh yeah.

## **Tammy Interview #2**

**Aki:** So could you talk about the most important relationships or maybe the most important relationship in your life?

**Participant:** Ok. I can see it breaking down into two periods. In my early life, my parents of course would have been the most important. And then once I became a parent, especially after I left my husband when my child was 2, 2 and a half, not quite 3. So from that point my son has been the most important relationship in my life. So I kind of see two different phases.

**A:** Ok. Could you talk about that second phase when your son was born, what that was like?

**P:** Well I remember all through the pregnancy thinking oh this is the easy part. You know, it's the next 18 years after he's born and I was afraid that I was going to break this baby. Which didn't make sense because I was the oldest of six and I had taken care of younger siblings but I was afraid. But as soon as the baby was put in my arms it was like everything became automatic for me. It was, its like I told somebody, I said my love for this baby is like breathing. It's just that natural of a part for me. It's not something I have to think about, it's not something I have to work at. Is just is.

**A:** It's very immediate and natural.

**P:** Mmhm. Yeah, yeah. And so an important thing for me as a mother was to make sure that Kyle would be himself. I didn't want to try and be one of those parents that try to make the child into a copy of themselves or to live through the child or have him achieve things that I wasn't able to. I certainly hoped that he would be able to achieve things but I wanted it to be his achievements. And the most important thing for me was that he be himself and that he like who he was. And I thought if he is comfortable with himself, that's going to be the most important thing for him making his way in the world. So that's what I saw my role as a mom, was helping him become himself.

**A:** How did that play out in your interactions with your son?

**P:** Gee. One of the things my mother said she noticed was a difference between the way she raised her children and the way I was raising Kyle, she said you talk a lot more. You explain while you're doing stuff a lot more than I ever did. And partly I think it was she had six children and Kyle's an only child. But I would listen to him and there were things that were not negotiable. I know a lot of parents, especially in my generation, tried to be their child's best friend and I don't feel that that is good for either of us. But I would listen and there were times I would compromise but there were certain things that there were no compromises on. Anything that involved definitely physical safety or right and

wrong things. I mean, I'm not quite sure how to explain that but you know other things I would listen to what he'd say and I would explain to him if I wasn't going to agree with what he wanted, why. And even if it were the safety and the good and bad kind of things I would explain why I was making my decisions. And that's what my mother said was very different from the way she raised us.

A: Do you have a story or two about how, where that actually happened?

P: My favorite compromise story was, we had baked gingerbread men and then we were sitting down for supper and it was time, I was fixing supper and he wanted to eat a cookie now and I said no you can have a cookie after you have supper. And he kept pushing and pushing and finally he said, "Can I eat the head now and have the rest of the cookie after supper?" And I said, ok sure. I said just eating part of the cookie isn't going to ruin your apatite and you'll eat the healthier parts of the meal too. And that was a thing, you have to make sure you get the healthy food before the treat. But I did compromise on you can eat the head off the cookie and have the rest later.

A: How old was he when this happened?

P: Three or four.

A: Ok.

P: Another three or four year old story came when- another food thing would be, you know he would not want to eat something. And I would say well you're three years old, eat three bites and then you don't have to finish it, if it was the vegetables that he didn't want. So we were at the playground and I said ok it's time to go home and he said I want to go down the slide three more times. And I went ok, he had to eat three bites of vegetables because he's three, he wants to slide three more times because he's three.

A: Did he comply with that easily?

P: Yeah. I think because he was part of making the rule and I tied it to something that was personal to him, then he was really happy to follow it. You know, I said three bites and he said three so I let him have input to it too. But we still were going home within a reasonable amount of time.

A: So at this point, his father was gone and it was...

P: He was seeing his father every other weekend and like one day, a few hours on the weekend in between when he didn't have a full weekend. But yeah it was basically Mom's house, Mom's rules.

A: Ok. Could you talk about how your relationship changed over the years with your son if it did change?

P: Oh absolutely. As he got older, and was able to understand more things and able- one of the good things that my mother did do with us was she raised, she said I'm raising you to be independent. You know, you aren't going to be able to- I'm not going to be there for you all the time. And so as he became older, was able to do more for himself, I would let him do more and let him have more say in a lot of the decisions that went on. Not that I stopped being the mom. And then things about the



relationship between his father and myself and the reasons for the divorce. Also as he was older and able to understand more, he would get a little bit more information from me on what had gone on in the relationship. As he started to experience things with his dad, I could say, you know this is what my experience was with your father to sort of help him negotiate that relationship.

A: How do you think that, how do you think he responded to that?

P: He seemed to do really well. There were some issues, I mean every kid has issues and we had a difficult year in middle school when he was 13 and you know that's a big transitional time. And I've heard a lot of parents have told me that it was like somebody stole my kid when he was 13 and substituted some ogre or somebody took away my child's sense of humor. And then once we got past that age then everything came out ok. But he had some issues with his dad and they involved that need for independence that kids go through in those teen years that his dad wasn't- and that was an issue in our relationship was that he just wanted to hang on too tightly and not give somebody significant in his life very much freedom or independence and so as Kyle was struggling with that with his father, I was able to share my experiences.

A: Ok. How did he affect you?

P: I actually joke that most parents stay together for the sake of the child and I left for the sake of the child. It was not the best relationship and I knew it but it wasn't until there was a child involved that you know, its one thing for me as an adult to make a decision to stay but its another to have a child and force this child to stay in what I knew was not going to be a good family situation. Also, when Kyle, when he was 12, right about the time he started to have the issues with the anger and the independence with his father, he wanted to change the visiting situation. The home environment there had deteriorated physically. His father had physical health issues and he was, his mental health was deteriorating with the physical health. And so I knew that the physical environment as well as the emotional environment weren't good. And so I did, it was a difficult decision to go back to court and you know I told Kyle, I said both of us are going to, he's going to be angry and we're going to be both of us bearing the brunt of his anger. And the relationship with him will get worse before-

A: Between him and his father?

P: Between Kyle and his father, between Kyle's father and myself is going to get worse until we get through this and the more I stand up to him the more he learned that I was not going to back down. And that was probably my biggest fault through the relationship was not dealing well with confrontation and backing off. And so when it came to having Kyle, and like I said I'm going, ok its one thing to do this for myself but for somebody else I was willing to be stronger, take a firmer stand and deal with the consequences of knowing that I was going to make him angry.

A: Not only for your sake but-

P: -but for Kyle's.

A: Two things that I could use some clarification on- one is when you say independence with his father, you mean independence from or independence with?

**P:** The biggest issue that Kyle had with his dad were things like he would say I want to do this or I want to spend less time in your home, I'm not as comfortable here. And his father would say your mother put you up to this or some friend of your mother's told you to say this. And he would not accept that this idea came from Kyle himself. So it was that sort of idea, the idea of Kyle wanting to maybe, instead of spending the weekend with Dad, spending the weekend with friends his own age. Somebody's having a sleepover or a birthday party or something and I would like to spend the time with my friends and change the weekend or instead of being with you. And that kind of, one of the things I told his father is you know, he isn't supposed to be spending- like my mother said, we aren't going to be there his entire life and his future is with his peers, not with us. And he needs to be able to establish relationships with people his own age. So it's that kind of, that moving away from being daddy's little boy to being his own person with his own ideas and his own thoughts and feelings. And being able to be comfortable expressing his feelings without being afraid he was going to make mom or dad angry or upset.

**A:** What was the relationship between you and Kyle like during this period?

**P:** It was still, there were times when it seemed like he was afraid, like I said to express his feelings. Because I knew him really well and I could tell and I could ask questions. We were still close. The anger was not directed at me and I believe that he knew that I was trying to help him with dealing with the situation. He was having some behavior issues at school but not at home. And I think that you know, something had to erupt somewhere and school ended up being the place where he had some issues.

**A:** Ok. I know that we are talking about something that is very private and intimate. Do you feel comfortable talking about it?

**P:** Mhm.

**A:** Ok. Just wanted to make sure. Ok so this was when he was 12 and 13. How did it change from there?

**P:** He was, we did end up going to court and we got him a guardian ad litem who was representing his point of view and who spoke with Kyle and we did end up also he was in counseling during this time and she was helping, his counselor was helping him to write a letter to his father. So between them working on that where he was able to put into very concise words what his thoughts and feelings were. The court coming out with a decision where Kyle was the one who could decide on when he wanted to visit. Which meant that he did not have to go visit his father anymore. I think he started to feel a lot more empowered and things got better both at school and away from school.

**A:** Ok. What was the relationship between you and Kyle like when that was happening?

**P:** We've always been very close. We always talked a lot and it was, and I think the relationship with me was pretty much- I'm going to sound really conceded. I think it was a constant for him and it was, I'm hoping he found it supportive. I think it was very good for him though because of him being an only child and me being a single mother, I think the counseling relationship was good for him to have a relationship with another adult where he could hear some values and ideas from another source and I get the impression- I very rarely was part of the counseling sessions. There were only a couple of times

when I would go in at the beginning to say there is some stuff that's happened that I think you need to be aware of. And it seemed like she was coming from a lot of the same places I was in talking to him, but I think it was good for him to have another source to get that from. He was not, during that time he didn't like to be hugged and touched and stuff.

**A:** From you.

**P:** From, yeah. And it was also some of the girls at school would tease him about not liking to be hugged. And that was difficult for me that I knew that where that was coming from was he couldn't say no to his dad but he could say no to me and know that it wouldn't affect my affection for him. So it was sort of a control thing. And when my brother died, that's when he started being more open to, I said you're going to have to put up with me hugging you from time to time and he had no problem with that. I mean, he was very open with that.

**A:** How old was he when this happened?

**P:** Let's see, that was 2004, and he was born in '91 so 13.

**A:** And if I may ask, how old were you when this happened?

**P:** I was 50.

**A:** This was in 2005?

**P:** 2004. 2005, then Kyleery's father passed away. And that was a big turning point for me. A couple weeks after his father's death, he said to me I've forgiven him mom. And I went phew, he's going to be ok. You know if he can say that after all that they've been through and at that point he had only talked to his father on the telephone for the past year at that point. And that was part of the agreement that he was able to work out going through counseling with the counselor about the visiting schedule and that kind of stuff. But for me that was a big relief.

**A:** It was a relief.

**P:** Yeah, because I had worried that if he weren't able to let go of the anger and with his father being gone there wasn't any chance for any kind of reconciliation, I kind of worried that that could be something that could become an issue.

**A:** Last week we talked about how your brother's death really influenced the way you look at death and how others might perceive when you pass away. Did Kyleery's father, did his death affect your thoughts about death at all?

**P:** His father was, he was older than I was about 16 years. He had health issues. When I married him I knew that because of the age difference and he was diabetic that it was very good odds that he would pass away before I would. At least, I figured you know, I'll probably spend the last 20-30 years without him. But at the time that he died, the year before that he had been in end stage renal failure. He was going for dialysis three times a week. And when that started we knew that it was a very short time. So this was not traumatic for me because of everything that I had gone through with him, I was

emotionally separated from him and had been for the ten years we had been separated, divorced before he died. So the emotional impact on me of his death was not anything traumatic for me. For me it was more the worry about what impact would it have on Kylerey to lose his father.

**A:** Ok. So could you talk more about the time that your brother passed away and how that affected the relationship that you have with Kylerey?

**P:** Yeah. That was, I was just recalling the day and Kyle had not been open to hugging for awhile and he knew that that was what I was going to need and he hugged me. And he let me hang onto his arm at the funeral and that was a turning point in his ability to start expressing physical affection with me again. Beginning as a comforting thing and then gradually it developed to the point where just the affection between us- I can hug him and he still doesn't initiate but he'll see me reach out and he'll reach out and hug me and pat me on the back and the whole thing.

**A:** That must have meant so much to you on the day of the funeral when you hugged.

**P:** Mmhm. Yeah.

**A:** What did it mean to you?

**P:** Well there was a combination of just the physical comfort for the pain that I was feeling. And the realization that Kylerey was opening up emotionally.

**A:** The physical comfort and Kylerey's openness, how did they affect- how did you feel about those things happening?

**P:** Well, I mean it was comforting. It was a comfort to have somebody that you care about express that care at a difficult time. At a time when I was losing somebody, I had just lost somebody with whom I shared affection. And to have somebody else there able to express affection. It would be very, very hard to be completely alone at a time like that and not know that there was someone who cared about how you were feeling. And of course my brother lived in Tennessee and had been there for all the time that Kylerey was alive so Kyle and the cousins here in Ohio didn't get to know him as well as my other brothers and sisters so they were all sad. My niece was, this woman had brought my niece and a friend home to her mother's house from a soccer practice and she said I've got to tell you about the conversation in the car. Sydney is my niece and her friend was asking well you must be really sad with your uncle dying and she said, "Well I am sad but he lived far away and I didn't know him very well, but my mother knew him all her life and so must be very, very sad." And she must've been 7, 8 at the time. And we were just all so touched at somebody that young realizing that yes, I'm sad but somebody else is also sad and has more reason to feel sad. You know that pretty much would express how Kylerey was feeling at the time too.

**A:** That care for the other person.

**P:** Yeah. Being sad himself but also caring about knowing that Uncle Bernie's family, his brothers and sisters would be even sadder.

**A:** And I'm not sure if you agree with me on this so please let me know, so when you and Kylerey

hugged it also sounded like Kylerey must have been sad but also he was caring about your sadness.

**P:** Exactly. And it was both knowing that he was able to feel sadness and knowing that he was able to care about me and to feel empathy with my sadness. That was very important for me.

**A:** That was eight years ago.

**P:** Yeah, yeah.

**A:** You had some thoughts or feelings, as I said eight years ago, what was that like?

**P:** I'm that old? (laughs). It's been that long. Yeah. Its kind of, you know sometimes it seems very far away and sometimes it seems very new.

**A:** How did your relationship with Kylerey develop from that point on to now?

**P:** Gee. I am still the mom but Mom has a much smaller role in his life. I remember when he turned 18, he said I'm an adult, I've got a passport and I've got money. I'm going to go see the pyramids in Mexico and you can't stop me (laughs). I said, yeah you're right, go ahead. But its getting more to the friend and confidant stage than it had been. Like I said you know I'll always be Mom, but Mom's role is more his biggest supporter than, well discipline with him was always really easy. I haven't been a disciplinarian. Rather than being the one who says this is the way to behave in this kind of a situation, we now have discussions about, we have some pretty deep discussions about ethics and philosophy and belief and I think both of us are still, I would like to think I'm still learning. And the learning from each other stream is now going more both ways whereas when he was younger I was more the source of information and ideas and now it's a whole lot more equal flow back and forth. Mutual learning, mutual growing. And I think we understand that each of us has areas that we're stronger in or we know more about than the other and respect that.

**A:** Last week we were talking about when we think about our own death, how it affects other people and you were concerned about Kylerey in particular. Could you talk more about those thoughts and concerns?

**P:** Probably the biggest concern is with him being an only child, with his father being gone, with his aunts and uncles and cousins not living in the same town is- who is going to be there to hug him when the phone call comes? That issue. Where will he find his support? Where will he find his comfort?

**A:** The act of hugging is a very meaningful thing in your relationship. So when you are gone, who is the one who is going to give him the hug.

**P:** Yes.

**A:** Ok.

**P:** I mean, family will be there but it's going to take them awhile to get here. Who's going to be there right away for him? And you know in the future he'll probably have a serious relationship, he may get married, may have children but in the meantime that's probably a big concern for me. Not ready to let

go yet and leave him on his own because I want him to have some kind of a support system.

**A:** Is there any kind of legacy or any kind of memories that you want Kylerey to have when you pass away?

**P:** Cookie baking comes into my head (laughs). I've been baking cookies for many years for that boy. Gee, I haven't really thought too much in terms of legacy. I hope that he'll always, I think he's always known that he was loved and I hope that he never forgets that he was loved. That is one thing that I have gotten from my family is I have always known that I have been loved unconditionally. They might not understand me, they might not agree with my choices, but by golly they love me and they'd be there for me no matter what. And I hope that that's how Kylerey thinks of me and I've certainly tried to let him know that no matter what you do and no matter choices you make, I might not be happy with some of your choices but I will always love you. And I hope that he has felt that throughout his life and I hope that that will always be with him, that that will sustain him in the future.

**A:** Thank you very much.

**P:** Yeah, I'm getting a little teary-eyed again.

**A:** Must be a very meaningful thing to talk about.

**P:** Yeah. Well its kind of interesting too to see some of the things that I have experienced within my family and to see them being passed on down. Some things I've done differently but I think that big thing- that unconditional love. I think that's a very important thing and I think that that is something that I got and I certainly hope that its something I pass on and I hope Kyle is able to pass that on.

**A:** That is a legacy. That unconditional love.

**P:** Yeah. In addition to his middle name by the way is Steven, which my first name is a form of and I was named for my father's mother who died when he was very young so I've sort of passed the name on through the family. You can leave that part out.

**A:** Ok. Is there anything else you want to talk about in terms of your views towards death or your relationship with Kylerey or others?

**P:** I guess another part of maybe legacy thinking about- this is going to go back to my religious beliefs, believing in God. And I believe that we are here to show God's love in the world. We're God's hands at work in the world and it goes back to the love and caring thing that I feel that we should do our best to care about other people, to be kind as much as possible. That that's our purpose in general as human beings, our purpose and I would like to think that I have been an example of that for Kyle. And that Kyle will then also continue to do what he can to help improve the lives of other people that he comes in contact with even if its just by being kind, by caring. You know, some of the volunteer work I do has been I think expressing that and it has been very good for me to see Kyle involved with volunteer work and to see him wanting to do something in his life to make some changes to help improve people's lives. So that would be another part of the legacy.

**A:** Ok. So your beliefs, your spirituality, your religiosity, that tie in with the legacy you want to pass on

in your relationship.

P: Yeah, well said. Thank you.

A: Yeah. Ok thank you very much. Is there anything else?

P: I don't think so.

A: Ok. Thank you so much.

### **Ed Interview #1**

Aki (A): Could you talk about what life is like right now for you?

Participant (B): You mean in terms of compensation or being satisfied with my lifestyle? Or...

A: With anything.

B: I- I feel particularly lucky at this point right now. Uh- one of the things that you may or may not have realized is that I have Parkinson's Disease. And that is something that does change your life quality. And in my case, the- uh- physician diagnosed it early enough that they were able to get me on medication that tends to keep it stable. That- it won't- it won't stop it forever, but it will- it helps the situation. And I feel extremely lucky in that respect. The bad part- the- the downside is that I've had to give up my practice. Uh- I was a- I was a doctor. And I've had to give that up. And I sort of ha- had- had identity- my identity was tied in with my profession. And now that I'm not the doctor that's at the clinic that people are used to coming to, I'm- I'm not anybody. I'm not a- a- any particular person. And that's- that's hard to take. So I- I see two very strong things pulling me both- each- each way. So...

A: K. When did you find out about the Parkinson's?

B: It was in- um- uh- uh- in March of- uh- oh- (pause) '03. Yeah- yeah- '03. So it's been- it's been about ten years since I've been diagnosed.

A: How did you react to it when you first found out?

B: Well, I had known for some months there was some process or another that was going on that wasn't normal. Uh- there are a- a variety of symptoms- about twenty-four common symptoms that they associate with Parkinson's Disease. And any two or three of- of those constitutes enough for a diagnosis usually. And um- so the- the presence of those things- it sort of lead me to believe that I had something going on. And I had the physician check, and sure enough, there was something going on. So we- went through the diagnostic process. They do a- I- uh- MRI and all the- old banner of tests. And uh- decided that- that's indeed what it- what it was. Uh- they- they wanted to make sure it wasn't- uh- ALS. And they wanted to make sure that it wasn't- uh- uh- what's the other one- (pause) uh- there's a- there's another disease that they- they compare it to that has to do with muscle strength and so- uh. But uh- Parkinson's is a- a deficiency of dopamine producing cell- cells. And dopamine producing cells are responsible for- uh- feeling good, feeling happy, ha- having- uh- control of your life and so forth. And uh- that wasn't very strongly- uh- evidence in the early stages, but as time went by, it became more and

more obvious. And so then there came a point at which we- we just had to decide that we were going to address this or we weren't. And we decided to- probably would be best because of my- the nature of my work- it being medicine, there are many fine points that go with that that I should probably stop while I could without- without doing any- any damage through accidents or. So yeah.

A: So out of duty, you didn't feel like you...

B: Yeah- yeah- one of the- one of the things that's very difficult with Parkinson's is convincing the patient that he shouldn't do su- and this and such. Or that it- it- it shouldn't- he shouldn't by a certain date- uh- he should give up something like driving. Um- they changed my license to say that I wasn't suppose to- not be driving. But they didn't- they didn't write the complete- uh- uh- license up, so I still do occasional- uh- short trips around town and so forth.

A: Okay. (pause) How did it feel when you finally got the diagnosis from the physician?

B: Again- uh- having- having been sort of prepared and not- not- uh- surprised completely. It- it didn't bother me so much. What- what bothered me more than anything was the fact that I knew that there would come a time when I would have to address some of these things. And that there were- are- uh- caregiver groups that are- that are trained to- uh- to- uh- offer day to day help with their patients- uh- for very- very frequently. It's the spouse of the par- of the patient. Um- and since I knew that was going to be the case, I began to look about for the possibility of- of a- a care- of a caregivers group that I could belong to- even though I didn't want to. Um- it sort of- it's sort of giving up your- um- autonomy to be diagnosed with something you know is eventually going to sap your strength and sap your ability to do things and so forth. Um- the- um- the- the variety of things can change. A- a- a- again, I was lucky because the two most common kinds of- of Parkinson's- one is the kind I have which is- uh- mainly stiffness in my joints. Um- I- I have to loosen up very much in the morning before I can move much. And the other is the Palsy- the- the quivering of the hands that you may have seen in- in patients. And I- I having had the- having been diagnosed at- the- knew that I had the- the- uh- Parkinson's with stiffness, and that again was a very positive kind of thing.

A: K. (pause) So when did you retire from your job?

B: Um- two years ago last month, which would be- oh- two thous- two thousand-

A: Ten?

B: Yeah, ten. Uh- and it was in- in October- uh- September.

A: Could you talk about what that's been like for you- retiring and...?

B: Uh- it's- it's the one thing that I think about daily. Um- what I can- what I can do- what I can't do- what I should do- what I shouldn't do things like that. Again, I'm- I'm very fortunate because the physician that I have has an interest in keeping me stable. And that helps me very much. The um- uh- (pause) let's see- lost my train of- there was something I was going to say, and I lost my train of thought. I'll think of it in a minute here. We'll just go ahead with the next question, and then I'll come back to it.



A: Sure. Sure. Um- you sa- talked a little bit about how- um- being uh- medicine- uh- being of that pro- uh- profession is something important to you.

B: Yes.

A: Um- could you talk a bit about losing that identity?

B: (pause) There- there are several factors that go along with that. The- the thing that made them- made that impression on me the most was- uh- when my wife said to me that a lot depends on- uh- uh- lot- uh- how'd she say- state that? The amount of time- the amount of time and effort that a patient goes through when their diagnosis is delivered to them is very telling in the kind of activity home- home life and activity that they have- the kind of sports life and activity that they have and things like that. Because they usually start searching for another job or another part of a job- uh- right away. And I didn't. I've- I've been putting it off- putting it off. And- and she asked me, "Well, what do you- why do you think you're putting this off? You know eventually, you're- you're going to have to admit that you just can't do any work." And so ultimately, I suppose I will. But it- the- um- the- the- the disability- uh- insurance payment that I get because I'm considered to be to- totally disabled. Um- uh- the- the regulations from that company state that if you can do any kind of work, you're suppose to do it, and if you can't, you're suppose to be a hundred percent- a hundred percent- uh- disabled. You don't- you're not allowed to do anything- uh- to get money or carry on any kind of a career and so forth. And so it- it was- it was- it was a mix of regulations and a mixture of- uh- things that I knew that the government would insist upon and things of the- uh- my insurance policies would- my disability insurance policy would insist upon. And- uh- you would have to get accustomed to that. Um- I- I still read magazines- uh- periodicals in my profession because I wanted- I want to know what's going on. I also- um- read management magazines for- for medical practices. And um- read about meetings that are coming on. And- uh- training seminars and so forth because I- I want to feel like I'm needed. The- the truth of the matter is nobody needs me anymore because of the- uh- fact that- with these policies, you're not allowed to do any work. The- one of the policies doesn't allow you to do any work. The other two policies uh- allow you to do- I think it's eighty percent of the amount of work that you were doing before. (pause) It's particularly difficult in my profession because what I'm doing is giving shots and doing surgery and taking x-rays and doing fine-point kinds of activities- things that- um- you- you- you don't dare make a mistake because you won't either diagnose it correctly or you won't diagnose it at all and have to repeat the procedure or at least find a- another way to get the right answer. And that- it runs the bill up- uh- endlessly. It means that the client is not going to get the best of care the first time around and may have to go around a second time to have that happen. And I didn't- I didn't want to do that to my clients. So I knew that I was going to eventually have to give up my practice. But I just can't come to terms with it. So- (pause) there- there will come a time when I won't be able to do many of the routine- daily things. Oh- well, in fact now, if I see a list of two, three, four things that I need to do around the house- sweep the sidewalk, wash the windows, whatever has to be done. I find that when I start to do these jobs, I don't have- since I- since I don't have the strength that I usually had, it takes me twice as long to do the job, which is frustrating to me because it means I can only do half as much work as I would normally have- have done in that period of time. And uh- little things like- uh- changing my clothes and putting on a- a shirt- uh- putting on a pair of pants or putting on a pair of socks takes longer than it used to. The um- many- many times have to have my wife- um- when I get dressed in the morning- grab a hold of my shirt and pull it on because I don't have the strength in my arms to- uh- to button my shirt and get it on adjusted and so forth like it needs to be. So that's been an adjustment that has had- had to be made. Um- there are some kinds of of clothing- some pieces of clothing that I just

don't even buy anymore- um- uh- slipover- uh- sweater- uh- always gets caught on my shoulders. I just can't- can't get it past my shoulders. So I- uh- quit wearing them because it wasn't worth it.

A: How does it feel having to make those adjustments?

B: (pause) It's okay at home because nobody- nobody's going to be- um- making fun of you, and everybody knows what's going wrong- going on- what's going on. Um- but- uh- when I'm out some place, like I sing in a- I sing in a church choir- and we have to wear these robes that the church choir wears. And I can't get the robe on. I finally learned how, but I- for a long time, I couldn't get the robe on. And I would have to ask somebody frequently- frequent- frequently a complete stranger to help me get my choir robe on, and it's- it's embarrassing because- um- it's something that shouldn't take- uh- any effort. My wife says that it probably the- the people that are helping you are probably just as happy to help you and make you- make your day smoother, which it- which it does. But- it- you still have to make that adjustment.

A: It's more embarrassing outside?

B: Mmhmm. Yeah. (pause) And the- one of the other things that is commonly- um- associated with it is the- um- ability to make- to- to make cognitive decisions. Um- I can't- it isn't- it isn't a serious problem, but it is a problem. And it kind of governs the re- rest of my activities because co- the cognitive things that I'm not able to do as well are things that- you can't tell me not to do them because you don't know exactly what the cognitive difficulty is in me. I may not be expressing what the cognitive difficulty is, so I've given you the wrong idea. And that is something that you're being misinformed. And as a professional, you don't want to be misinformed when they're- they're dealing with helping me and my- my diagnosis. But- so I can't say to you- it's okay if I don't do a job that involves surgery that I can do despite cognitive diff- dys- dysfunction, but that's not true. Because this cognitive dys- dysfunction may be si- significant and may be life-threatening if I- if something goes wrong.

A: You may damage your patients.

B: Exactly. Exactly (pause) And that- and when that kind of thing became obvious to me, in my surgical practice- the- the surgeries were taking longer, and they were- I was beginning to have little- little difficulties that were- uh- easily corrected but- uh- sh- shouldn't have had to correct anything. You- you want to have a surgery- you want to get in, get out. And uh- if you can't do that, you probably shouldn't be doing the surgery. So...

A: Did something actually happen during surgery that made you want to say this is it, I'm going to quit?

B: There were- there were a few episodes of- o- over the years, not- not just- not just in the past- recent past- but over the years where- um- I had- I would have to go back in to- uh- stem a bleeding- blood vessel, which is not an unusual thing to have done. You- you don't- you- you shouldn't have to do anything like that. And it should never ha- hap- hap- happen to happen. But it does happen. It- it- surgical mistakes like that occasionally do happen. And so I was- I was just as well off being advised to not do surgery, which I did- I- since it became obvious that I was having difficulty. Mainly I- I'm a very- uh- uh- I'm a very cautious person- I tend to be very conservative. And when it came obvi-

became obvious to me that I was having to do things that I should- have only had to do once and be done with it. The- the- the- to tie a particular blood vessel and so forth. Uh- when I- when I got to the point where I was having to watch that blood vessel for a period of minutes to make sure that it was tied cor- correctly, I knew that I was getting to the point that probably- I was spending more time than I should in surgery. And- just as- adjusted to much- little to do with that as needed.

A: Hmm. (pause) could you talk- um- a little bit about how you see your life unfolding from here?

B: What I don't know is- uh- what to expect in terms of time- (pause) in- in the det- the deterioration of the- uh- muscles that the dopamine- dopamine was taking care of. Um- if I had a magical- if I had a crystal ball that I could see forward, I would cast it probably what it will show is- uh- about every five to ten years there are changes that I can point to that will probably tell me that either I'm getting better or worse- one thing or another. And that- very likely there'll be some steps- uh- orthopedic- uh- devices that I'll need to get around the house. You- you ha- you haven't seen our house, so you don't know this- this, but all of the major doorways are double in size. Uh- be- because there- there may come a time when I get- when I stumble and fall, and my wife won't be able to lift me. And they'll need to get the emergency people in to get their- their carrier in. And um- there are five or six things that we've done to the major- the main bathroom that allow me in a wheelchair to take a bath. And um- the- that they've- they've done some things with the height of the stool in there. The um- it's- it's- uh- there's a roll-in shower and- uh- just a few things like that that we've done to the house here and there preparing for the- uh- inevitability of needing to make orthopedic devices of some value to me. Um- I- I re- I regret that my wife will have to make a decision about those things 'cause it- it's- it's not fair for somebody else to have to deal with the- the infirm individual. Uh- she married me for better or worse, and that's one of the worse parts of it. But- and she doesn't complain. But uh- there will- there will come a time when I'll have to make those decisions, and that'll- that'll- that'll be even rougher than it is right now. (pause) The- the- many of the- um- day-to-day things that I didn't expect- didn't- didn't realize would start happening but then when they did, I understood what I was seeing. Uh- there's a- there's a dead expression of the facial muscles, and you've noticed it in my face- how- how I look like I'm mad and- uh- actually I'm not. It's just that the- the tension of the muscles in the- the face are- is relaxing. And as a- as a result, I look like I'm frowning, and I'm- and I'm upset. Um- my voice is much more husky than it was before. Uh- people lean forward real close to me and listen to me I- I discovered in- in watching their action- that they were simply trying to hear me. They- uh- they couldn't hear. You can hear how my voice quavers from uh- trying to catch the right word without having to go through my whole panel-play of words. It's- it's kind of tough to pick the right word.

A: K. (pause) So all these things you foresee, do you think about your life ending?

B: I- I think only in the sense that I know that it will- not that it will necessarily have anything to do with the Parkinson's or- uh- anything to do with- uh- an accident in a- in a car or- uh- falling down the stairs or so. In fact, I was quite curious- um- through- throughout the month of August- uh- I guess more like September. I was- I was quite curious about how people actually accomplished dying when- when they have something wrong with them. And I a bo- I found a book called- uh- (pause) let's see- how- oh- it's called How We Die. And it's- it was written by- uh- a- uh- neurological surgeon in New York City- uh- actually Massachusetts. And um- very interesting book. It told what happens to the various systems- the various organs in- in- in dying- in the process of dying. And what the- um- outcome is and what is likely to cause it and what is not likely to cause it. And so- a lot of things about- uh- categorizing what kinds- kinds of dying there are. There's suicide, and there's- uh- uh- an auto

accident that you caused by yourself, which is also a suicide. And uh- alcoholism. And um- deterioration- major- major problems like the- and last disease. Um- which helped me figure out that probably what'll happen is I'll probably get pneumonia. Uh- unless there's something else that rears its ugly head in the meantime with me. But probably pneumonia. Mainly because the- um- uh- period as- as there's more and more deterioration results in a lack of swallowing mechanism keeping up. And as a result, you tend to get- uh- infections in the throat and eventually, into the lungs. And you die. (pause) I- I've often thought that it would be much more- uh- much better outcome to simply- um- drive- drive the car off the highway into a tree and just let the families sort out the details. But- uh- I've never thought about it to the extent of- uh- anything more than just wondering.

A: What makes one better than the other?

B: Um- the- the thing that I think is- is absolutely critical is- uh- one of the- uh- tenets of euthanasia is that we practiced in our medical practice, and that is that there- there has to be instant- uh- unconsciousness. What they do with animals is they use a bullet- shoot him in the head. And as soon as the head- as soon as the head bone fractures, they immediately go unconscious. And then they- they do the rest of it- the procedure. And with humans- um- any- anything that would be fast would be better than- than not. Uh- I- I would never ever want to do it with through drowning. I- I'm scared enough of the water to even to swim playing in water. And I would just want to make sure that it wasn't- wouldn't happen. And in fact, I put a hammer in each of our cars just so that after having seen a television segment on- on- uh- drowning in a car that gets trapped in the water. And they- they would have a hammer that they could break the window and get out. Uh- it- it seems kind of silly to me now, but at the time I thought it was pretty important. Um.

A: Mmhmm. (pause) So how do you feel about death? Is that something you fear or something you are curious about- something that you accept?

B: I don't get a pit in my stomach when I think about death. I don't- um- (pause) I- (pause) I- I have- I have done a little bit of looking about the specifics of how- how we die. Uh- which has helped me understand what kinds of things I- I couldn't do if I decided I wanted to do- something like that. Um- I- I- the- one of the difficulties with planning- planning your death is that when you get it planned, you're too late to do anything about it. You can't- uh- accomplish the process yourself. And I- I be- I would then- then think about something like Dr. Caborian and his- his work. Um- and- then- then it would begin to seem silly to me, so I wouldn't think about it anymore. (pause) But um- I- I- I don't- I don't feel that it- that my death must be a suicide. But I surely don't want to have to foist on my wife and family the- the care that goes with deteriorating- the conditions. My wife's- uh- mother is- uh- in the full throws of Alzheimer's at the facility, the Knolls on- on the edge of town there. And um- sh- she's- she's nothing but a shell. She- she has no ability to speak. She can't- she's confined to wheelchair, and actually, she's confined to- to the Alzheimer's unit. And um- she- she has no- no quality of life. Uh- they feed her, and she functions, and that's her life. And that I wouldn't want.

A: So if you were to be someone who is- who needs taken care of, and you don't want the process to prolong be- because of your family- because you think about your family taking care of you?

B: Right. It- it- it- it's- it's their job to perhaps see to the details of- of- uh- planned death. But it- it should never be foisted on them. It shouldn't be something that they have handed to them and say- okay, it's your turn to take care of your- your father or your- your uncle or your son, uh- and uh- here's

what you have to do. I just- just wouldn't want to do that.

A: Okay. Um- at one point you mentioned you don't think about things like euthanasia or suicide- doing that anymore, was there a point in your- um in the past where you did think about doing that?

B: Not seriously. But- but yes because I- I want to know what really happens when death occurs. The- the death that we institute to animals that are sick beyond repair or can't- uh- be helped anymore, is a series of steps that are designed by a committee that knows the various things that go right and go wrong. And that then gives them- gives physicians some idea of what good death would be. But we don't allow good deaths- euthanasia. So there's no point in spending a great deal of time figuring out the way that's going to work because you can't work it- uh- without- without being illegal. So...

A: So- so the policy affected your decision not to...

B: It- it made it very likely that I wasn't going to be able to make anymore decision about it.

A: K. K. (pause) Were there other- other reasons why you thought that what- that might not be a good idea?

B: Euthanasia?

A: Right. Yeah. (pause) In your own case.

B: Yes, I- I really- I really very strongly feel that if anything struck me as being done specifically because the family had to make a major change due to my health. Uh- uh- I would then immediately begin to think more seriously about it. Um- I- I- it- it wasn't their fault I got sick. It is a- it was a- it's a disease that- uh- proceeds slowly enough that I can make changes in my life quality and my lifestyle before it happens to me. Uh- before hand- before it's handed to me. And since I have those options- I- uh- I- I just- I don't know that I could stand getting up in the morning and realizing that I had to- every single morning- had to spend an extra hour getting ready because I- I couldn't do it myself. And my wife had to help with that, and that extended her day. And just made it difficult for everybody. (pause) And- it- we have in our family- uh- three- three grown children, and one of them is mar- actually two of them are married. And um- the third one's going to get married this coming summer. The- and I would- I want so much for them to have as much time as they want to have or need to have being- being young- being full of- uh- uh vitality and desire to do things that they would enjoy doing. My- my son has a band in New York City. And uh- he- he's doing quite well. And um- I- if- if he had to because I became very ill- if he had to give that up, I would feel very- very bad about that. (pause) I- I just think that there are- there are so much- so much that they need and want to do that they- they don't need to take care of dad. (pause) So...

A: K. The attitude that you have towards death right now- has that always been the case? Has it changed over the years?

B: Since I didn't have Parkinson's until a few- few years ago- um- my- my outlook on- uh- death has- has changed a lot. The um- I- I just didn't really- didn't really give much serious consideration to something like- uh- suicide. But- but probably would now that there's the Parkinson's has been a part

of the problem. Um- I don't know how much trouble it would take before I would decide that I needed to do something about it. I just haven't- haven't really thought of it that way. (pause) And I wouldn't want- well- we have a- we have a- a group that we belong to that meets every Wednesday for supper- year-round- every Wednesday. And um- the- uh- it's- it's simply called potluck. And in the course of that organization coming and going and people- people arriving and moving to here and moving to there and so forth and getting involved. Uh- one family lost a son in an auto accident. And um- it has meant- there's been some major changes in their life quality. They- it happened probably- probably ten years ago- maybe not quite that much when we had the accident. But I- I just heard this past weekend that apparently his- his mother still- uh- has- has- uh- bouts of- uh- crying and screaming and- uh- why me Lord kinds of- kinds of things. And um- I wouldn't want my friends to have- feel like they had to help Cathy get through something like that. And Cathy's my wife. Um- I- I just- I- I don't think it's fair for them to have to do anything more than express the fact that they're sorry for- uh- things the way they are with- with my family. But- but they- they shouldn't have to do anything more than that.

A: In the events that you...

B: Should I be getting worse. And it- it would be- it was being- going to be obvious that there would be major changes ahead- things that would have to have some attention drawn to them. (pause) I guess that's- I- I can't- uh- I can't particularly think of other things that- that make it- make a major difference.

A: (pause) A major difference in...

B: How I feel about planned death. (pause) Yeah, when I think about- um- how I would be answering these questions if I did not have Parkinson's- um- I think it- it's a scary thought, but I think I probably should plan my death. Uh- but- it- I never sat down and did A, B, and C and what- whatever had to be done. Uh- so I- I guess I really can't say that I taken that- that counsel very seriously.

A: Uh- huh. (pause) Um- so if you- if you did- let me see if I got this right. If you didn't have Parkinson's- um- you wouldn't have- or you would have planned death? Or...

B: I- I would not probably have...

A: You probably would not have planned death. Okay. Huh. (pause) What would you have- what was your attitude like when you didn't have Parkinson's?

B: (pause) I thought that I was in pretty good health. I thought I had was keeping myself in pretty decent shape. I- I- if I had my choice of whether I wanted to be active or sedentary, I generally chose to be active with things like chopping wood and- uh- gardening and occasional things like that. Um- things that I- I can do now, but they require more time as I said before. Um- and um- so I tend to be- uh- critical about what I can and can't plan to do. Then um- when I- when I was not planning my death, I also- um- would try some things that I wouldn't try now. Um- running a marathon and so forth. I- I- I've never run a marathon, but I would try if I wanted to. Uh- with the- with the- without having Parkinson's. But I would never I doubt try it with Parkinson's. So that- that's one- uh- definite change. Um- uh- I- I don't- I haven't ridden a horse in- in many many years. I used to ride horses when I was younger. But I- I wouldn't- I wouldn't- um- hesitate to get on a horse and try to make it do what it's suppose to do. But I might find very quickly that I can't control it like I should be able to. And that's

been the kind of thing that's been happening- an occasional- uh- episode as time has gone by- things that I thought I could do and could do at one time or another I- I can't do anymore. So...

A: (pause) Back when you didn't have Parkinson's, did you ever think about death at all? Or was that...

B: One of the first things that I did when I was diagnosed was to find quite- uh- as much information as I could- eh- about Parkinson's- what it does and what it doesn't do. And so I- I felt- uh- pretty much well-informed, and it didn't- it didn't bother me particularly that I had Parkinson's. What bothered me was that in the first six to twelve months after my diagnosis, I was still making changes- physiologic and pathologic changes associated with the disease. That was the period of time when I was learning how to put my shirt on, learning how to pu- tie my shoes, learning how to brush my teeth. I- I- I learned how to- um- do all my grooming with the opposite hand- simply because that was the hand I could use to get the work done. And um- I also taught myself to- uh- write backwards- I mean write with my- uh- with my non-dominant hand. And um- just recently, I I've discovered that there- many of those things that I was doing to accommodate my di- infirmity- I have quit doing. I write with my dominant hand again. And I- and having fewer people lean in and listen to me as if they can't hear me. Uh- and I- I find myself doing more active- uh- work like chopping the trees down. Uh- in other words, I think probably that I should give the credit to the physician for having gotten the right mix of medicine. I take three or four tablets a day, which is nothing compared to most Parkinson's pa- pa- patients. Uh- some of them take as many as twenty and thirty- uh- twenty and twenty-five tablets a day. And I don't ever want to have to do that. But I may suppose- I suppose I may have to do that sometime. Uh- but- uh- at this point I don't have to. So that- that was- uh- something that I had to deal with. Um- what I- I used to pride myself on walking faster than my wife. And I'd have to wait for her to hurry up and catch up with me. And about ten years ago when- when I was just ready to have myself examined to see if I had something, I noticed I was having trouble keeping up with my son playing soccer. And I was- and I passed it off as- to the fact that I had to wear- I had at the time on heavy work boots. And I couldn't move my feet as fast as he- his because of those heavy work boots. But then I played soccer with him without the work boots, and I still couldn't beat him. So the- the- uh- that particular change sort of- sort of started the- the ball rolling with things that I was seeing- that I could tell were not right.

A: Hmm. (pause) So in- in response to the question of did you ever think about death before experiencing these things...

B: Only occasionally. And- and not to the point that I felt I must- I must settle the situation and must have a plan for death immediately. I didn't- didn't do that.

A: Hmm. (pause) Did you have thoughts about what death will be like for you before Parkinson's?

B: (pause) I don't think I really thought about what death would be like until I got to the point where I was curious about how I die- how I would die.

A: Okay. So only after the Parkinson's?

B: Yeah. Yeah. (pause) I kid my wife a lot about- I mean she's a- she's a full professor here. I- I kid her about- um- what she- what she will do after I'm gone. And um- you know- I think she- that she should be a consultant and go to Washington and do- do some more things with her career 'cause she's still

young enough she can. And um- good- in good enough shape profession- professional-wise that- that she could take on- take on an advising job of some sort. Uh- and- or some kind of a consulting job in- in Washington. But um- (pause) but I don't- I don't think about that- about what- what she should do as much lately as I used to. It wasn't as serious. It wasn't as likely that I would have to make that decision or help with that decision. So I- I didn't- um- it didn't bother me that much. But then of course as time went by, and things began to get worse and- a little bit at a time- uh- it got to the point where I had to think about the possibility of- uh- overseeing my death.

A: (pause) What do you exactly mean by planning death- overseeing death?

B: (pause) Making sure that- (pause) making sure that- (pause) let's see- how would I- how would I state it. (pause) Making sure if I could that it wasn't painful- that it was quick and immediate. That it resulted in- uh- no pain because of it's being instantaneous. And somehow, making sure that the lawyers and the insurance people don't have- don't make it rough for her to get what's due her from the various policies and so forth that we- well- keep. In other words, I- I would want her to be able to turn her attention to whatever she would- would rather do than take care of my affairs. Uh- she could- she could- she- she should have time to mourn. And she should have time to be sorrowful if she wants to be or be happy if she wants to be. (laughs) Uh- but- the uh- the- the various things that- that have to happen around a death- I would- I would hope that she was- was not- was not- um- called upon to do it against her will or- uh- unexpectedly.

A: (pause) Okay. Do you actually mean planning to die at a certain point? Do you have a plan for that? Or...

B: Or- or should I just when the spirit moves me just drive my car off the highway? Uh- (pause) I don't know. (pause) I- I- I don't- I don't know- um- (pause) how seriously- it would have to get before I would start planning for my death. And because I don't know that- it makes it real difficult to- to answer the- the question. Be- because I- I- I think that it would be out of my hands at a certain point, and that then would be a big- a major part of the key as to what I would- as to when I should be doing that kind of death planning.

A: Hmm. So it's not that time yet.

B: I don't feel so.

A: K. (pause) Hmm. (pause) Let me ask you- um- this could be the last question- um- what is death to you? Very general question.

B: (pause) It's- death to me (pause) is the cessation of life quality, (pause) which happens to include a conscious appear- a conscious ability (pause) to either enjoy or not enjoy life. To- um- to be able to qua- quantitatively list what kinds of things- uh- constitute that quality of life. And when those things cease to be enjoyed and when there's no further enjoyment participated and when the- the- when the present state of affairs is such that- the- the quality of life has no- has no meaning at all, then- then the body is- is done. I don't- I don't feel that I'm- I'm going to ride- walk up on a sunny hillside and meet Jesus or anything like that- I don't- that doesn't- that isn't a part of my makeup. Uh- but I- I am a little bit afraid just a- just a smidgen that it might hurt. And I don't want it to hurt. So I would- would probably be planning very carefully- uh- to- to choose that part of the euthanasia process was- was well



taken care of. So- so I wouldn't have to worry about it. (pause) So- well, I hope that you think that you got some information that you can use.

A: I sure did. Is there anything else- um- that you want to talk about that you feel like you left out?

B: No. I can't think of anything that I- in the past couple days that I wanted to- to ask you that I have forgot them.

## **Ed Interview #2**

Aki (A): So could you identify the most important relationship in your life?

Participant (B): The most important relationship?

A: Uh-huh.

B: Well, that's going to be a tough question. Uh- uh- there are several that I should chose fro- (coughs) from. One being my marriage- uh- I always- I always- when people tell me the most important thing that ever happened to me, that's usually what I reco- recommend is that I- I was married. And uh- to a wonderful person. Um- uh- the relationship between my- my family and myself is- is going- (coughs) extremely important. I mentioned in last week's interview that- um- there are few- few- uh- relationships that I have as close to- as- as I do to relatives. So that would be a second one to choose from. A third one to choose from would be- uh- I had a- I had a- a friend or two in college- another male friend who- um- was- was roommate with, and we spent a lot of time together and did a lot of growing up together and so forth. But while that was an important relationship, it wasn't as important as my wife or my family. I think probably my wife.

A: Okay. Let's talk about her. How did you meet her?

B: Um- when- uh- when I was- uh- going to medical school, I was living in Columbus at the time. And um- I- I had been- been doing some singing in a church choir there, and the conductor of the church choir had- had a wife that was very kind to- to me. And uh- one thanksgiving- uh- holiday, she arranged to have me come to their house for- uh- part of the thanksgiving meal because I was stuck in Columbus taking care of the animals. And uh- she thought it would be nice if I had a place to go have dinner, which it was. And we went there, and she took me around the house and showed me all the pictures of the various kids- there were five kids. And- uh- indicated that one was their daughter from Colorado, and this- this was her picture. She wasn't a particularly flattering picture, but I- I said, "Oh, okay." Well, about ten days later, I get a call from the conductor of the chorus. And he- um- said that he needed a tenor- another tenor voice- what I sang. Well, by this time I met every- everybody in the family except my wife. And uh- so I said okay- uh- I'll sing there. Came to the first rehearsal, and uh- there- there she was. (coughs) 'Scuse me. (coughs) And there she was. And uh- she's a- she's a very- um- active, bright, cheery person, and so she kind of dominated the conversation in the- in the room, which I made fun of. And I shouldn't have done that. That didn't go over very well. But I- I- I- about another five, six weeks later, I decided to date her and see how things turned out. And they turned out fine.

A: Hmm. Okay. So this was a room full of people or was it just you and her?

B: That- doing- doing what?

A: When you first saw her.

B: It was a room full of people. Yes. (pause) Yeah. She had- uh- recently completed her master's degree at the University of Denver and had come back and was- was working at- uh- Ohio State University in the- in the psychology area. And uh- I- I figured she'd probably be there for a long time, so I wouldn't have to worry about where she was.

A: Mmhmm. (Pause) What was your relationship like at first?

B: (pause) It was- at that- that age and stage in- in American youth, you usually spent- (coughs) spent some- some time just simply thrusting and parrying and uh- um- throwing out questions and seeing how the other person answers them. And finding out that you both like chocolate shakes or you both like mocha shakes or neither of you like mocha shakes or- you know- the little things like that that kind of form the boundaries- the- the nebula's boundaries that- within which that person resides. And um- and I had a similar take on my various personal quirks and so forth. And um- then you- you quickly learn that there are some places where these- these figures cross paths and that there's a common bond there of one sort or another. And then it goes- goes from there. I knew- I knew from the time I had decided that I was going to date her and see what it was going to be like- that she was probably going to be the one that I ended up with. I wasn't going to let her get away. Uh- she- she was obvious- an obvious good catch. She was a smart person. She was quick. She was courteous. She was- she- she loved people, and people loved her. And she had- uh- uh- degrees- those- she was smart. And uh- I- I really think I'm lucky to have landed her.

A: Mmhmm. How old were you when...?

B: Uh- I graduated from my- bachelor's degree when I was twenty-one. And then- uh- medical school was four more years. It was that fourth years, so that was what- twenty-five years? Twenty- twenty-yeah. And then we dated for a couple years and then got married.

A: Okay. K. Do you have a- a story or something from that period with her?

B: Well, the- the- the part of the story that I usually tell is that- the first time I came to the choir rehearsal after her father had- uh- asked me to- to come, uh- she was being giddy and silly and carrying on. And I- I said to somebody who was sitting beside me- I said, "Who is that girl? Why is she acting so weird?" And he said, "Well, that's the conductor's daughter." Oh- I said, "Well, she's got nice thighs." And that wasn't such a- do you- do you happen to know- um- Jack Lyles? Uh...

A: No.

B: He- he- he was the marching band- uh- in- leader here for many many years. But he and I sat next to each other at Ohio State in that same choir. So- but the- the- the story really was that I- I was at first not totally impressed, but eventually I was.

A: Huh. And then you- um- were you the who talked to her first?

B: Um- (pause) I don't remember how that happened- uh- what the sequence of events was. She- she was active enough to say there were no- there were no- uh- strangers to her. I mean everyone was her friend. And uh- so she- uh- she was easy to approach because of that. (pause) Yeah, that was a long time ago.

A: Hmm. It looks like you were thinking about something.

B: I was just thinking about how long ago that was. (laughs) Quite a while ago. We- um- started dating in '71. Got married in '73. And uh- it's all down hill from there. (pause) So what's your next question?

A: What was the marriage like at first?

B: What was the marriage like?

A: Mmhmm.

B: The- the bond? The...

A: Yeah. What was the interaction like?

B: Um- it was unique because she liked to do things that were important, and she liked to do them herself. So she was many times creating things to happen by doing it herself. And that included our- that included our wedding. Um- for instance, she- she had the number of buttons on the front of the wedding gown that I had asked her to be my hu- to be my wife. I figured I was going to live until I was ninety-nine. Yeah, I doubt if I'll make it, but anyway. And then because that- that would take so- so many buttons on the- on the- um- when we walked down the aisle, we each walked down an aisle. And uh- that has- had never been done before as far as I know. Um- the- we had- uh- a- my grandfather, my wife's uncle, and a regular minister- all three participate in the ceremony. And that was a pretty heavy load of ministers- kind of unusual. And um- she didn't want a diamond ring. She still doesn't have a diamond ring. And uh- and that- that was a little- pretty unusual for girls at that time- that- without the ring, you just didn't have a wedding. So- but it worked out fine for us. Um- let's see- what other things. It was a relatively small wedding, and we- we had our reception at the faculty club at Ohio State University. Um- but I have nothing but good memories of it. It- it was- it was wonderful and made all the more so by how personal she- she made it. She created it. And uh- so- (pause) I guess that would be- those would be the special things about the wedding.

A: K. What was the marriage life like?

B: (pause) Pretty hectic because she, being full-time at her- at her job, was often busy. And then she- of course- course quit that job after we got married, and she moved up to Vermont. And we searched and searched for a job for her and couldn't find one that was suitable for her degree of- uh- education. And so for a year she did nothing but- uh- putter about making- she made me a suit. And uh- doing things like she took lessons on how to stuff furniture. And um- she took- I think she took some other art- art lessons of some sort or another. But I don't remember exactly what they were. And um- she- despite the fact that- uh- all these various things were not down her alley- they were not a part of her profession, she seemed to be quite happy taking them on and playing- playing with them and having a good time. So I guess I- you- you'd- you'd say that our wedding- our marriage at that time was pretty busy. We-

and we did a lot of hiking. We- we didn't have children at the time of course. We did a lot of hiking and snowshoeing in the winter. And uh- uh- just all the local kinds of things that were fun to do. (pause) We- we- we didn't seem to have real good common sense about our cars because we would pile into the car and drive back to Ohio on a moment's notice just to have a quick hello to the relatives and drive back to Vermont. It was- it was a good ten hours each way. And uh- but because- uh- we were willing to do that, we therefore, had the ability to maintain the close contact with our relatives. And there were some relatives in the Boston area that we visited on a regular basis too.

A: (pause) So a lot of travelling?

B: Mmhmm. Yeah. She and I would just did- did- did- it took less than an- less than an instant for us to get ready to go for a trip (pause) 'cause we enjoyed seeing our relatives so much.

A: Hmm. (pause) So meeting her relatives and her meeting your relatives and...

B: Everybody pretty much knew everybody. Yeah. (pause) In fact, we- our- our- our honeymoon- um- we spent in- in Maine at a friends- uh- lo- lodge. And uh- we're- we were going to spend- I don't know- three or five days there before we went back to work. But after about two days, when we had enough sitting around, and went back to work.

A: So it was hectic like you said.

B: It was hectic. Yeah.

A: Uh-huh. (pause) How did your relationship with her change over the years, if it has?

B: It has- it has changed. I would suggest that she has a much stronger role in- uh- planning of things that I thought I had as my providence when we got married. Um- none- not no one particular thing. But several things- uh- budgeting and- uh- whether to make large purchases- um- you know- re- refrigerator- or freezer, stove- things like that. The- those bigger- bigger items I- I- I thought that I was making most of the decision. But as it turned out in hindsight, probably she had as much of a role as- as I did. It was pretty equal. Um- (pause) let's see- she- uh- (pause) she- she had a habit of- if she was going on a- a- shopping jaunt- or similar type activity, she would also extend that to include some interesting looking store that she hadn't planned to be the- taking- take time for. And we'd come home with something really unique. We- one time she went to an auction, and in- in Vermont, the auctions continue year-round. And even when there's snow on the ground, you go to the auctions. And this one farm auction that she went to, she bought a bo- uh- box of- uh- books just 'cause they were just selling them for a dollar. And the box was huge. It was like this table here. And uh- it turned- it turned out at the bottom of that box was a seventeen- 1731 medical text, which is invaluable to me. It might not be to others, but it certainly is to me. And I still have it and been trying to keep it in good shape. But that's the kind of thing- if she hadn't decided to stop at that auction and buy a- and buy a whole box of books for a dollar, then we wouldn't have had those items. And so I- I got to the point where in general, I- I defer to her judgment on those items 'cause she's usually right when it comes to value and style. I'm not the author that- that she does that. (pause)

A: So the role that either of you- um- played changed over the years?

B: Mmhmm. Yeah. She- she became much- much more of a leader in terms of purchases and budget and things like that. Yeah.

A: Were there- uh- any changes for you in your interactions with her?

B: (pause) Gosh. I- I- I don't- when I think of our relationship and how we got along, I- I don't- um- I don't see major changes in my- my- my way of thinking. Um- she- she would surprise me by- um- doing something like- like I'd come home, and a room would be painted that I didn't know she thought needed to be painted. And uh- it was done well. So- you know- there was just any number of things that there were- as time went by, there were changes, but they were just kind of routine, slow-paced kinds of changes. There was nothing major. She didn't go out and sell one car and buy two cars or anything like that. She was sensible about the purchases. (pause) Guess that's- that's about it as far as purchases go.

A: Hmm. Let me- uh- ask you a different question. How- how did she affect you as a person?

B: Do you- by that do you mean- how did she cause me to change? Or how does she cause me to not change? Or...

A: In any direction. Any way. (pause) If they- if she did have any influence on kind of the person...

B: Yeah. As- as time went- as time went by- um- and- and she would participate in- in these purchases, and crafts, and things like that. There were many things that I came to accept and- uh- would- would quit doing. Um- I don't clean- I used to clean the house. I don't clean the house anymore. Uh- that- that kind of thing. There were many- many small changes of that nature that in our marriage just si- seemed to sort of have happen just because they needed to be done. It wasn't that we both went on a- any kind of a safari and tried to fix up the house. It was just a matter of something needed to be done, so I'd let her do it 'cause she generally did it better than I did. So...

A: Mmhmm. Were there- was there any influence in your- uh- internally? So personalities- um...

B: Changes you mean?

A: Right.

B: (pause) The things that we've done- the major things that we've done- major trips and major purchases and so forth, have pretty much been done with common agreement between us. And for that reason, I- I would suggest that there haven't been such major changes as there might have been if- if I- I- and I say this guardedly- if I- um- (pause) uh- if I undertook something major, I would in general defer to her judgment before I did anything. And sometimes to- to do the thing- uh- it's- to- to not- to not do it myself- and let her do it. Um- she- she's been a go-getter right from the start. And she goes and gets better than I do. So...

A: (laughs) So this was a trust that was developed over the years? Am I right in thinking that?

B: Yes. I- I feel extremely fortunate that I- that I've been able to have a wife that I can trust- uh- for- for any number of reasons. The- um- main- well, probably the main reason being that I- my- uh- my ego doesn't suffer as much if I know that I have trusted in her that I need to get things done. So...

A: Could you break down that sentence for me- your ego doesn't suffer as much with that trust?

B: I have a fairly strong ego. But I have also- have a- it's kind of a- well, I guess you- I guess you would say less of a strong- uh- personal strength- uh- personal sense of duty and so forth. And so I'm- I'm more willing to knowing that she is going to do a better job, talk to her, get a better idea about who's going to do it and then let her do it. Because she- she just get it done better than I will. It was a surprise to me when I offered to do some painting at the hou- around the house, and she forbade me to do it. And I- that- that took me by surprise when that happened.

A: When did this happen?

B: Hmm. It's been many years ago- probably thirty years ago. (pause)

A: How did it surprise you?

B: Uh- it was one of those things that we'd never really done together- uh- little painting jobs- touching up here and touching up there- she would do. But a big job like painting an entire house or something like that was- was something that I- I was ready to tackle, but she wouldn't- she wouldn't let me. And I don't know whether it's because she knew that I was not going to get it done soon or that I wasn't going to get it done well or I wasn't going to get it done at all. So I- I just- I'm just not sure how that transpired. But that's sort of the way that it played out.

A: How did it feel- um- as she said that- she told you?

B: (pause) It felt a little bit like she- like she might- despite the quality of trust that we had between us, that she might have decided that this was one thing that- that wasn't that critical to have that be a trust issue- uh- she'll just do it. (pause) I can't think of any other items that- (pause) there- there were- there was one- one item that- um- we lived in a- another house here in town. And we had redone some of the interior of it. And one of the things that we had- had been redone was the kitchen counter and the kitchen floor. Well, they- one- the floor was gray, and the counter was green. And when we got them installed, she decided she didn't like it. And within a matter of days, it was ripped out and another counter put in. And I thought- oh God, we're in- we can't live like this. But she didn't change it any more than that. So it was okay. But that- that shot a little bit of adrenaline through me when I came home, and the counter had been ripped out and another one put in.

A: Huh. So is this- what- what was the emotion? Like there's a surprise and do you feel a little angry? Do you feel a little shocked? Do you- what...

B: A little angry. Yes. Uh- huh. A little- a little bit of shock in the sense that here- here she had done something that- on her own that I didn't anticipate. She did- she did a decent job of getting it done. I mean it was installed by workmen. Uh- but she did a good job of getting it arranged and so forth. And everything really was going to be fine despite the fact that I was upset that she had- she had- uh- put a new counter in. So...

A: (pause) Uh- did these surprises- uh- increase, decrease change over the years?

B: (pause) They- they changed. It didn't- I- I don't think of them as having increased or decreased. But they changed. Uh- um- she and I both enjoyed vocal music- performing vocal music. And um- we had- uh- for a couple years sung with the Main Festival Chorus in Cincinnati. And after our first child was born, we decided we wanted to have that extra time with our child rather than running back and forth to concerts down in Cincinnati. And so we dropped out of that- that, and I- I was real reluctant for her to have to do that because she so thoroughly enjoys vocal music herself. She's- she's trained- trained voice. And so she after a period of time, organized a group here in town that subsequent to that organize- organizing effort spent the next twenty-five years singing with this group. We got a conductor that was from Miami. And uh- we- we gave usually two or three concerts a year. And it allowed her to do the kind of singing that she enjoyed but didn't have to make the trip to Cincinnati. And- and it- she was just kind of a- a go-to kind of a person. She saw something that she wanted, and she went toward. And that's sort of the way she was- (pause) is. (pause) And then there were- uh- some other things that we did with our kids that- uh- were- were- uh- not- not instigated by her but approved by her. One in particular she- uh- she played the- um- harlot in- uh- Aveda. And it was- it was funny, and it was sad, it was happy and so forth. I- I made it point- a point to- um- tryout for the place that the kids were going to be in. Because I figured that if I was going to enjoy their being in the play, I would have to be right there with them on stage. So then I would be onstage as to tryout for a part. So I tried out for a part. I was in several plays with them. And she was in sev- several other plays also- also. And all three of our kids were in plays. So that was- uh- that was- uh- that was a surprise in- in that she was willing and able and wanted to- to do that. But it was a happy, pleasant surprise.

A: Uh-huh. So the emotions that came with the surprise were different each time?

B: Yes. Yes. Mmmhmm.

A: Last week we talked about- um- you receiving the diagnosis of Parkinson's and then eventually you retiring from your job- uh- that you took very seriously. I was wondering- um- about your relationship as- uh- from that time period- um- to now- what it was like with your wife.

B: The- the diagnose period you mean?

A: Yes.

B: And you're interested in the- the relationship between my wife?

A: Right.

B: And...

A: Around that time.

B: Around that time. (pause) Well, I don't- (pause) I had so- I had so said it in my mind that I was not going to be dependent on others. That for a long time, I re- I rejected her attempts to help me adopt a life quality that I should have adopted a long time before that. She- she knew that I was going to be needing special furniture and special equipment- um- special ways for eating and so forth- some of which I've already adopted. But- uh- some of them I haven't gotten around to yet. Um- the- (pause) the- the presence of- uh- the malady- um- she- her- her attitude was let's be proactive, let's get going

with what we need to do to help you. And she- she would scour magazines and- and go to- uh- uh- flea markets and stores where- where they might have things that were- equipment that could be used. It- it- for a long time- it- while I was getting used- accustomed to the disease- um- I had trouble- uh- getting- getting myself fed and getting my daily washing my face- and things like that- getting that done. It was kind of a tough thing to do. Eventually, I got to the point where I trained myself to eat- eat- or write with either hand. And that allowed me to have some more freedom. But she was way ahead of me on all those things. And- uh- she wanted to have me try a variety of occupational therapy kinds of things, which I didn't want to try and ha- haven't yet. Uh- but she didn't press the issue. She said, "K. If that's the way you want to have it, that's the way we'll have it." And uh- so she- she maintained her ideals- her standards and waited for me to catch up- which is- which is what happened. I eventually caught up and was able to dress myself and other things. So- (pause) I guess that's- I think that sums it up pretty well. And that's one of those things that I look back now, and I say to myself, "Thank God I was introduced to her. And thanks God- I- I- thank God I married her. And thank God we have a marriage that has- has lasted all these years and still seems strong." So...

A: It still seems strong?

B: Oh I think so.

A: Uh-huh. What tells you that?

B: We can- we can get in a fight and go to bed, kiss, and make up (pause) in- instead of letting the fight spoil the day. I think probably I have- uh- less of a feeling of adequacy in- in a fight than- than she does. And that also is- makes it hard for me because- um- my- again my- uh- my ego is so turned sideways sometimes that it's hard to- it's hard to argue with her. (pause) Well, let's see (pause) does that cover that- the feelings that I'm supposed to convey?

A: Mmhmm. Yeah. The- uh- I was also curious about after you retired- um- you were talking last week about preparing for death. And- um- I was wondering how she fits into this, if- if she does- um- come into the picture of- um- how you want to spend the rest of your life.

B: (pause) I feel very strongly. I don't- don't know whether it was on the other tape or not- that- that I stated this. But I feel very strongly that I don't want her to have to make changes in her ca- professional curriculum in her teaching load, in her religious habits, and her- um- her- her ideals of fun- uh- picnics, parties, whatever. I don't want her to have to change that because of me. And having discovered that she's a strong person, and that she usually always hits the correct answer right on the nose, it has- it has allowed me to relax a little bit about this Parkinson's even though I don't know what it's going to be like to have further deterioration. There will be other things that will be deteriorating that I'll have to depend on her for. And I'm- and I will want to be able to count on her being- um- de- differential to- to me when I need it and not when I don't need it. Uh- I- I don't want to be babied.

A: Hmm. (pause) Why not?

B: (pause) I have always felt that it was- it was her province to have the kind of job she had prepared for through many years of training that- that she- that had been instilled in her by her- her folks who- who are very strong-willed people. And who had- and she- she was also- uh- uh- brothers and sisters too- some strong family members. And I just didn't figure that it was correct for her to have to change



her quality of life to be appreciative for the rest of her life.

A: So for her sake?

B: For her sake. Yeah. (pause) I'll- I- I- it- it- it- of course it's a very difficult thing to call- call- course to call because we don't know what happens after death. And so I may be- may be foolish for me to worry about it because I don't know. But also that's the reason I guess not to worry.

A: (pause) It- um- fits with the- uh- your thoughts on death that you talked about last week where life just ends.

B: Mmhmm. Yes. (pause) I- I still find- I was just writing a letter- uh- to a friend of mine who has Parkinson's disease. And uh- I wrote that it's- um- (pause) it- the- he- he was stating that it- he leaves it up to God- that God dictates that this is what he'll have and that's what he'll have and he'll get by until he can't. But- um- (pause) I- that- that doesn't- that kind of- uh- attitude doesn't necessarily fit with my interpretation.

A: Okay. (pause) A little bit ago you talked about- um- your relationship still staying strong. Um- now that you are looking into death, so to speak- um- has that affected the relationship in any way?

B: (pause) It's hard for me to- to evaluate that correctly. And I'll tell you why. My mother-in-law- her mother has fulminate- uh- Alzheimer's. And she's- she's a shell of a person. She's not really a personality anymore. Uh- her fa- my wife's father is ninety-four years old, and he- he's got the vitality and the appetite of a sixty year old. He- there just isn't anything that he'll- he won't do. And I have- um- a variety of philosophies in the various relatives on her side of the family. Some are independent kinds of people. Some are gay folks. Some are- um- back to the earth kinds of folks. Uh- some are very- one- one young man is a- uh- flutist with the- uh- one of the New York Philharmonic orchestras. So it- it run- they run the gamut from top to bottom. And that- that would indicate that she would probably be able to maintain a life quality simply because there is somebody in the family that would be able to support her whatever she needs to have done. But she also is strong enough, old enough, wise enough that she could do it herself. So- I don't- I don't- uh- worry too much about her being able to find something to do. And for that reason I don't worry about her.

A: Um- sorry maybe I was confusing in my question. Um- has your awareness about- um- your disease, about death, has it affect the- the way that you interact with her?

B: (pause) Okay. Um- yes, I think so because we- there have been probably greater nu- a greater number of instances since my diagnosis of things that she and I both know we're right about and obviously, one of us has to be wrong. But the- uh- there have been more- uh- tussles over- um- little things since the diagnosis. Not- not to the point that I feel that we're drifting apart or anything like that. It's just a matter of- uh- promoting our own ideas I guess would probably be the best way to think of it. My- my idea of promoting that is to drive the car until I can't drive the car. She on the other hand, would prefer that I quit driving the car before there's any doubt at all because the- that might be too late if there's an accident. So...

A: Hmm. (pause) Has there been any changes- um- in the way that you feel about her?

B: (pause) Yeah. I think of- I think more of her- uh- let's see- how should I say this. I think on a greater number of occasions I think of her as a- a partner- a business partner, a loving partner, a family partner, a- um- (pause) well, that- that- that about covers it. That- the kinds of things that typically would be the result of decisions made by the- the- uh- the- the whole family- the whole partnership. And uh- (pause) and as- as a result, I think less about some of the partnership things that we do that- that require a lot of thinking, a lot of work, a lot of- uh- sweat- and blood, sweat, and tears. There are fe- there are fewer of those than there used to be. We've gotten to the point where we've to some extent know how the other one's going to act- react, and so there's no point in getting into an argument. You just put it on a shelf and say to hell with it. (pause)

A: As you- uh- when you pass away, are there any legacies that you want to leave behind to her?

B: (pause) I'm not sure what a legacy is. How- how would you describe the legacy that you're thinking of?

A: Sure. Refr- let me- let me refra- reframe my question. Um- is there anything that you want her to remember you for- for anything?

B: (pause) It's interesting that you ask that today because just a week ago- um- I was a part of discussion group that was suppose to put down on a piece of paper a term that defined them that had- that hadn't been used by in- in the conference by that point. And I put down congenial. And I was telling Cathy about that, and uh- she said, "Yeah, that's right." She- she said, "You're- you're congenial. That's a good word for you." So I guess that would be the- the thing that I would- uh- feel was (pause) I think I lost my train of thought there. Try- try the question again.

A: Is there anything- um- that you want her to remember you for?

B: Oh that's right. Okay. Um- yes, congeniality would be fine for her to remember me by. (pause) I- I don't have any- um- notions that I'm going to win any awards for dying or before I die for that matter. The- um- it would have been- it would have been nice- (pause) there was a- (pause) there was a time at which the- the clinic that I was- that my partner and I had built was brand new. And at that time, the city- every year would nominate a business of the year. And I thought we probably would get that because it's usually who everybody knew. But we didn't. And my- my goal was to- when I did finally retire, have some kind of a blurb for historical remembrance. So that somebody could look at that particular issue of the local newspaper and say, "Oh yeah. I remember Dr. Maroot practiced from such and such time through such and such time." And uh- it would be something that would be a part of local history. That didn't happen. And it pissed me off. But it- that's the way it goes. And uh- so I- I have to learn to put up with that frustration. And um- I guess- I guess the congeniality is- is the key word there. Yeah.

A: Okay. Congeniality?

B: Congeniality. Yeah.

A: How is it meaningful to you?

B: It- it speaks to interaction without stress, which has always been- I can remember my father teaching

me that when I was at- at his knees as a kid. He was a relatively quiet man, and he would- his- his philosophy involved a- that kind of belief. And so I tended to pick that up. (pause) It- uh- congenial- the- the term congenial also- it- uh- also means what I see as a resolution or a so- solution of an argument or something that is- is involved in a very upsetting. I- I hate being upset, and I don't like it when others make me upset. And- so it- congeniality would- would be the solution that I would see through most- for- for most of the problems that are minor kinds of things that we deal with on a day-to-day basis.

A: Okay. When you say "we deal with on a day-to-day basis"...

B: Well, my wife and I.

A: Okay. (pause) This- uh- brings me to my last question, which is in a very general way, what is your wife to you?

B: (pause) That's a good question. It's well thought out. (pause) Because I want to say what will give you the right impression and that's a hard thing to do because you haven't lived with her and- and been married to her and so forth, and I have. What is my wife to me? (pause) I think it probably has to do with congeniality. Um- she is- she is a barrier between me- my personality and the world because she can handle the situations that I have trouble with. She- she can handle the tiffs and the neighborhood relations and the- she can stand up at a meeting and talk to somebody and argue with them. And uh- in the public eye, and I would no more do that than kiss a pig. (laughs) But um- my- my- my bent toward congeniality would- would prevent me from doing something like that because it would- it would mean that I might get somebody who would have a strong re- response, and I would- I would be out of luck. I wouldn't know how to argue with them. So I would have to sit down and take the shame of having thought I was going to- but- do a solution and not do it. Um- congeniality has to do with keeping the family relations good, and- and she does. She's sort of the center of the family's activities. Um- (pause) I- I'd say my wife is my- (pause) my bucket full of congeniality. Does that give you some idea like- like I know?

A: It was a very open-ended question. I just wanted to see what you had to say?

B: Yup. Um- (pause) did we cover the things we should?

A: Yeah. Is there anything that you want to- uh- say before we end this interview about your wife, about death, about anything?

B: I ended up saying a whole lot more about my wife than I thought I would. I'm not sure whether it's my fault or your fault. Uh- but it must have been important or we wouldn't have ended up there.

A: Mmhmm. K. Are you okay with everything that you talked about?

B: Yes. Yes.

Quinn Interview #1

Participant (B): Already told you about my father died of cancer? And my mother kept sending me to

get the neigh- uh- neighbor- ne- neighbors- the neighbors, and she didn't want me in the room. So I don't know why she kept sending me out.

Aki (A): She kept calling the neighbors? (coughs)

B: And she told me to go to the neighbors and ask them to come.

A: What do you think she was thinking?

B: She wanted someone to tell her exactly when he died. And that one neighbor said, "Hold up a mirror in front of his face, and if it doesn't- it doesn't get smeared up- why- he's gone."

A: Mmhmm. (pause) Wow. You said- you said you wanted to see him in his deathbed?

B: Yeah we seen him after he died. And we called the undertaker.

A: What was it like seeing him dead?

B: Well, I knew he was dying- he was dead. But- uh- it doesn't bother me that he was- and I- and I had an uncle that was getting ready for church, and he dropped over dead. Some people go so fast, and others, they go so slow.

A: Mmhmm. (coughs) And he was just fast? Your uncle?

B: What?

A: He was fast? He died fast?

B: Yeah. He was getting ready to go to church and uh- his sister found him laying on the bed dead.

A: Wow. Were you close to him? Your uncle? (coughs)

B: Yeah- uh- uh- he used to come out and help butcher. And he always brought us oranges- oranges. So we- we looked forward to seeing Uncle Henry. But he wouldn't stay and eat with us.

A: Okay. (pause) Why not?

B: I don't know. (laughs) We never did find out. All we know is he- when he was- when we were ready to eat, he went- was ready to go home.

A: Huh. (pause) So those were the uh- the moments that you remember- those were memorable moments of- of dying. What does- what does death mean to you?

B: It means going to Heaven.

A: Okay. (pause) So your uncle and father went to Heaven?

B: Yeah, I think everybody goes to Heaven.

A: Everyone goes to Heaven? Okay.

B: Yeah- that- that has been good on this Earth. (pause) And my mother died in here.

A: Your mother?

B: Yeah, she was in here for couple uh- uh two years, and she died in here.

A: This nursing home? (coughs)

B: Yeah. I was here, and that- they wanted me to give her some- something to drink. And re- she refused to drink. So we went home, and it wasn't long after they called me and said, "She's gone."

A: Okay. What was it like seeing your mother die?

B: I didn't see her die. I just (pause) knew she was getting ready to die 'cause the nurses told me.

A: Okay. (pause) What is it like going through that- having that knowledge?

B: I don't know. It's not different from anything else in life. (pause) You have to prepare for everything.

A: You have to prepare. Okay.

B: Mmhmm.

A: (pause) Okay. Can you um- can you talk about the time that you entered this nursing home. How did you come here?

B: I had an operation in a retirement home where I stayed. They didn't have a nurse there to take care of you after you come home from the hospital. So I decided the nursing home would be right for me. And I've been here fifteen years.

A: Fifteen years? Okay.

B: Yeah.

A: What was it like spending fifteen years here?

B: It wasn't too bad at first. But now it- they don't have the help they need. And they won't be getting it unless they get more people in here.

A: It's lacking people?

B: Hmm?

A: It's lacking people?

B: Yeah, lacking residents.

A: Okay. K. (pause) So how do you like your life here?

B: Ah- it's okay. I can do what I want to do. And I just went through some therapy, and I told them I was tired of it, and they just quit it then.

A: What kind of therapy?

B: Uh- all kinds of therapy. One- a couple of them they did me where I get up and do the things. And- uh- she had me walk a few- from the door to this chair. (pause) And- and they had- had me get in and out of my chair- in and out of this chair. But I can't- can't come out of this chair as easy I should. But I still try.

A: Okay. (pause) But you quit doing that?

B: Quit the therapy? Yeah. The one therapist- all she did was play games with me and cards.

A: Hearts?

B: Cards.

A: Cards, okay. You didn't like that?

B: No- (mumbles) I enjoyed it. (laughs)

A: Okay. Do you- do you think about death a lot here?

B: What?

A: Do you think about dying?

B: Yeah, every once in a while I wonder why I'm still here since I'm eighty-five year- eighty-six years old. And I thought well, it's about time for me to go.

A: You wonder when you- that it's about time?

B: Yeah, I think it's about time. I'm wondering why the good Lord doesn't call me.

A: Okay. (pause) Have you always felt like that?

B: Not until recently.

A: Mmhmm. What was it like before?

B: I didn't even think of death before. And just like my mother and father died, and my older brother died. And my one sister died.

A: In that order- your brother, your- your sister?

B: No, my sister died first. And that's just when I come home from an operation, I could go and see her laid out or anything, but I realized she was gone. And then my brother died after he had uh- uh hemorrhage- uh- on his brain. What do they call them, aneurism or something like that? Yeah, and- and they thought he was strong enough to live in a nursing home. They had him in a nursing home for over a year. I think it was about nine months he died there.

A: Okay. When was that?

B: It was back in nineteen- no twenty oh three.

A: Okay- twenty- okay. So- uh- eight years ago or something like that?

B: Yeah.

A: Okay. What was it like um- what was it like going through your siblings' deaths?

B: Uh- it wasn't- uh- anything special. Just watch- see them laid out.

A: Oh- okay. Was it sad? Or...

B: No. No. We prayed the Rosary and- and things like that.

A: Uh-huh. (pause) Okay. But these events made you think of your own death more?

B: Not until I ca- after I was here a while that I thought about...

A: Okay. (pause) I see. Did you have any- uh- fear or any- any- were you scared of death before? Or...

B: No. I- I- (door closes) I knew it- that something had to be done. And that was it.

A: Mmhmm. (pause) So you always thought it was going to happen and...

B: Yeah, I knew that would happen someday.

A: Uh-huh. (pause) And now you're wondering...

B: Why it isn't happening now.

A: Okay. Okay. What does it mean that you're still alive?

B: It means the good Lord isn't ready for me yet. One time I kept wondering why I wasn't dying, and all of a sudden, and I s- s- mind or something said, "This is your guardian angel, and God isn't ready

for you yet.”

A: Okay (pause) How- how does it feel that He’s not ready for you to die yet?

B: I don’t know. I have to just wait until He’s ready. And one time- uh- after I come back from the hospital, I felt like I was just floating around in the air. And it wasn’t long after which they tried to push something back in me. And I woke up. (pause)

A: Uh-huh. Wow. So you’re floating- you felt like you’re floating.

B: Yeah, in the air. And it wasn’t too long when something come and push it back- push me back in my body.

A: Was that like- uh- maybe like ascending to Heaven? And then you were like brought back to Earth or something like that?

B: No, I didn’t go dead- just floating around.

A: Okay. (pause) How- how- what do you make of that?

B: I don’t know what to make of it. (pause) It gave me the idea that dying i- isn’t hard to do. Some people they find it so hard when they’re sick, and they can’t die.

A: Okay. (pause) What- what- why ought to- what makes you- what makes you different?

B: Hmm?

A: Sorry. What makes you- uh- what makes you different in your attitude?

B: (pause) I don’t know. (pause) I knew my sister was dying ‘cause she had so many things wrong with her. (pause) And she died after I come home from the hospital, so I didn’t get to her funeral. And my brother- he was in the nursing home for a while. And my other brother that takes care of me- he told me I should go visit him, and I didn’t think I wanted to visit him laying in bed and nothing- doing- not able to do anything. But they said, “You have to come and see him.” So one day he came and took me over there. We seeing him laying there and then wasn’t doing a thing for himself. And it just di- didn’t look right to let him die- uh- let him lie like that. It wasn’t too long after she put him in a di- different nursing home, and he died.

A: (pause) Huh. (pause) Was there any feeling as you saw him?

B: No. I just go back to the idea that I don’t want to see him like that.

A: Okay. He was in pain? Your...

B: No. No, he wasn’t in pain or anything. He’s just laying there (pause) like in a coma.

A: Okay. (pause) He wasn’t doing anything?



B: No. Nurses were doing everything for him- washing him and- be-be getting up, laid in bed and- (pause) in fact they were doing something for him when we came. And they- they said, "Well, you can go in now." And then they were finished.

A: You had a lot of family deaths in sequence?

B: Not too much. My father died in 1971 and my mother in 1991. So that was twenty years that I- I was with my mother.

A: How were your siblings?

B: Okay. Uh- one brother that was right next to me was one I would always work with. We had- we had things we had to do two at a time- two- um- at a time. And he was always my partner to do the thing- help with the things. So I felt closer to him than any of the other brothers (pause) or sisters.

A: Did you feel anything- um- when he died?

B: When who died?

A: When your brother- your most important one.

B: He didn't die yet. The one I told you was next to me- he hasn't died. It was the older one that died. There was eight of us.

A: Wow.

B: Yeah.

A: Pretty big family.

B: Yeah, and we were close. We a- always ate meals together. Other people don't do that anymore. They- the children have different things they have to go to. And they don't have a family dinner anymore.

A: Right. Do you guys live close to each other?

B: Yeah, we all lived in one house and stayed there all the time. Until we started working o- out. My- my brother worked for a farmer to- to- so he wouldn't have to go to the service. But he- later on he went to the service. And my other brother worked for a farmer later on- he- he was in business with him. He sold eggs in the city. And what eggs he had left, he took them to a market to sell.

A: Huh. (pause) Nice. Um- how do you- how do you think you'll spend the rest of your life?

B: Probably in here until I die.

A: Okay. How do you want to spend it?

B: Doing what I like to do- my knitting and reading books. I read the magazines I get.

A: (pause) What kind of magazines?

B: I get the Catholic Digest, the Reader's Digest, and Good Old Days. I enjoy Good Old Days because they tell us things that happened years ago, and it's always interesting.

A: Okay. What about it is so interesting?

B: There sometimes things in there that I used to do too. And one- one article had something about the road that I lived on. They said that it- they were picking- what were they- I don't remember what they were doing, but we read- they wrote that it was doing an [REDACTED] (14:25) [REDACTED] on the road I lived on.

A: Okay. So you felt close to it 'cause you used to live there?

B: Yeah.

A: Okay. Okay. So what's going to happen to you after- when you die?

B: I hope to go to Heaven. I'm trying hard to- to- uh- get ready for Heaven.

A: How exactly do you mean- getting ready?

B: I pray the Rosary everyday and say my night prayers. And- and make sure I talk to Jesus a little bit in the evening.

A: Okay. So talking to- um- the higher beings?

B: What?

A: Talking to the higher beings?

B: Yeah.

A: Okay. (pause) Do you feel nervous at all- uh- being tested?

B: No. Though I was in the hospital for about four days and didn't know- remember thinking about it.

A: How- okay- say that again.

B: I was in the hospital about four days and didn't remember thinking about it. And uh, all I remember is a man standing behind me and says, "You coming too?" So they sent me back here.

A: The man behind you told you to uh- come back here?

B: Yeah, he said, "She's coming out of it. You can take her home now."

A: You don't remember any of the experience in the hospital?

B: No, I don't- I didn't even know I was in there until I got back home, and they told me I was in the hospital for three days.

A: Oh wow. That's a long time- three days.

B: Yeah. And I didn't remember a thing about it.

A: Was there ever a point when you felt like you were going to Heaven- you were dying?

B: Yeah. I think about what a wonderful place Heaven must be. Don't you feel that you're going to Heaven when you die?

A: I hope so.

B: You hope so. (laughs)

A: (pause) So tell me about Heaven. What's that place going to be like?

B: I don't know exactly, but I know it's a pl- going to be a place where stay the rest of the uh- rest of your- the rest- uh- your life- or like- you're going to stay there until the end of time.

A: What does it- what does it take to go there?

B: Being good. And (pause) taking care of yourself and helping others.

A: Do you think you do well in that respect?

B: Oh yeah because I- at church I serve as a Eucharistic minister. And when I came to the retirement home, I used to take the Eucharist to the people in the rooms that couldn't get out. And that was a big experience. I had a hundred year old lady, and she said she wasn't worthy to receive communion. And I said, "How about if I prayed the Euchar- uh- Act of Contrition with you?" And she said, "Not even that'd help." I kept wondering what a lady a hundred years old would've done. (laughs)

A: (laughs) Wow. (pause) So death- you've been thinking about that um- pretty recently. Bef- before that you didn't really think of it?

B: No, I didn't even think of it.

A: Okay. But now that you're thinking about it, you don't really feel any fear or anything?

B: No, I don't feel fear- fear to die.

A: And you feel comfortable talking about it?

B: Yeah.

A: Any excitement there? Or what's that like?

B: Any excitement? What do you mean?

A: Going to Heaven and...

B: Oh. No, I don't know exactly what it's going to be like, but I know that I'll enjoy it.

A: Okay. Okay. Um- (pause) okay. (pause) So no fear whatsoever, huh?

B: What?

A: No fear whatsoever?

B: No. Nuh-uh.

A: K. (pause) Could you talk more about uh- (pause) how you uh- came to think about death? Um- how it changed for you over the years?

B: Well, until recently, I didn't even think of it. I knew it was coming, but I didn't think of it- it like I- I do now- that I wanted to go. And when my ma- mother died, I went to a retirement home, and I stayed there until I got sick and then come here. And uh, I was twenty years with my mother.

A: (pause) Is that what triggered it- to think about death? Or...

B: No. Uh-uh. My father had cancer, and he was uh- suffering something awful before he died. And my mother had cancer too, but she didn't have the suffering that my father had.

A: Okay. So- s- suffering- that's going- that's going to affect like how people experience death?

B: Yeah.

A: Okay. Is there any suffering for you?

B: Yeah, I get pains and aches. And they give me some medicine, and it helps.

A: Okay. (pause) Does that make you uh- dislike the dying process?

B: No. Uh-uh. I feel comfortable with it. I know it has to come, so why- uh- fight it?

A: Uh-huh. (pause) Uh-huh. You never fought against it?

B: No. Uh-uh. No.

A: Uh-huh. (pause) What- what made you think about death so recently?

B: I'm not sure, but I just started thinking about it. And when I turned eighty-six, I thought, "Oh, that's

long enough. It's about time I was to get going."

A: When was your birthday?

B: August the second.

A: Oh wow. That was pretty recent.

B: Mmhmm.

A: (pause) Okay. So you turned eighty-six, and you thought you'd be going soon?

B: Yeah. (pause) I thought it was about time I go.

A: And right now- like how are you feeling about it? Do you feel- do you think each day if you're going to die or not?

B: Yeah. Wake up in the morning, and I'm still here. Mmhmm. I have a- a lady I write to, she says the same thing. She's in her eighties too, and she just- she wakes up every morning and says, "I'm still here."

A: Okay. (pause) What kind of emotion is it? You wake up and you- you think, "Oh, I'm still here"?

B: Oh, it just feels like I have another day to look forward to. Try to get through.

A: Try to get through?

B: Mmhmm.

A: Okay. What was life like for you, Rita?

B: Well, we lived on a farm, and we had to work. The girls had to work out in the field as much as the boys. We had to hoe the garden and cut core and shut core and everything that come along. And feed the cows and- uh water them. In the wintertime, my father kept the cows in the barn 'cause he thought it was too cold for them outside. So we had to take a bucket- take- get water from a pump and take it up to the ba- to the cow's trough- put it in trough and go get some water. We had to keep it on until they got through drinking it. And we'd go to the next one.

A: So you worked hard?

B: Yeah. We had to work hard. We mil- I milked two- two cows morning and evening. Mmhmm.

A: So this was your father's farm?

B: Mmhmm. And my younger brothers they had a milking machine that they used, so they didn't ever- uh- had to milk cows. And most of the machine did the hard work.

A: Wow (pause) So it seems like you had a- you had a pretty- uh- strong relationship with your- your- your father. Although you said you weren't really close to him.

B: (pause) No, I wasn't really close to him. But when we went to town together, we talked a lot.

A: Okay. (pause) What was it like to- uh- to know that he was dying?

B: Uh- I knew it was coming, so I didn't- didn't think anything of it.

A: K. (pause) So you- you were working on the farm for a little bit and then- and then you moved out? You worked?

B: No. I- uh- when they took me out of high school, my father said a girl has to learn to cook and keep house. And so he got me a job doing housework. I did that for eleven years. And then I went to- uh- business school. I learned how to use a comp. And I got a job at CGE, and I never used the comp that much there, but I did other things that were interesting. Like take care of the uh- engineers and their papers. And uh, things that had to go with that- they have um- on the- sending out the- to the district- what the district should do. And when they come back home, I had to close out the uh- jobs center- to the engineer- and get it round- to get- back on the- maps and stuff like that.

A: Okay. (pause) Okay. And you were there for a long time?

B: Uh- twenty-seven years.

A: (pause) Wow. (pause) When did you uh- finish there?

B: Uh- 1985. January eighty-five.

A: Uh-huh. (pause) And then you retired?

B: Yes, I retired and stayed home with my mother. At first I could go out and do things for myself and not worry about her. But later she went blind, and I couldn't leave her alone. So I had to get my brother or sister to come stay with her while I- if I wanted to go out. My sister came when I was shopping- when I come home she said, "Mom kept saying where's Rita." (laughs)

A: (laughs) So you were pretty close to your mother?

B: No, I wasn't too close to my mother.

A: Oh, you weren't? Okay.

B: No, I just took care of her. Uh- I felt I was responsible for her.

A: You felt responsible?

B: Yeah. And see that she could get- get in and out okay. And- and she wanted to go every place I went, so I had to take her along.

A: Was it just you out of all the siblings who took care of her?

B: No, the others were all married and had their family of their own. My one sister- her husband had died- she'd come up once in a while to help me a little bit.

A: Uh-huh. K. You never married?

B: No, I never married.

A: Okay. (pause) How did you like your life?

B: Well, I look back, and I remember things that I did that I enjoyed. Like going on vacation- went to Dorrance on vacation- learned to ride a horse. And had a lot of fun there. And I went on trips too. I went out to California to the missions out there. The missions in the desert out there. And a [REDACTED] (26:50)- to see the house that the Indians lived in- they called it a [REDACTED]. And it was just- it's circle-like, and they all lived inside of that. The whole family lived inside of that. And I went up on a mountain where the Hopi Indians lived, and they- they were nice. They tried to show us everything that's up there.

A: Mmhmm. Wow. So- so you like travelling, huh?

B: Yeah.

A: Okay. Vacations and stuff.

B: Yeah, I went down to the Smoky Mountains too and enjoyed that. Mmhmm. They're beautiful down there.

A: Okay. Okay. So you look back on life and you remember all those places?

B: Yeah, all those things I did. And I don't regret that I never got married. I used to wonder why, but I do- don't anymore.

A: You used to wonder why you weren't married?

B: Mmhmm.

A: Okay. What made a difference? What changed it?

B: When I realized that there was no one out there for me to marry. The men that wanted me- I didn't want them. So- (pause) and my father got one that was over ten years older than me, and he wanted me to go out with him. And I didn't want to go. So...

A: You didn't like him?

B: No, I just like liked him, but he was too old for me.

A: Okay. (pause) Uh-huh. (pause) So you were- you were alone?

B: Mmhmm. My younger brother takes care of my business- pays the bills and sees that I get the things done.

A: Mmhmm. And you have no regrets about that?

B: No. (pause) I figured the good Lord didn't want me to get married. That's why He didn't send anybody.

A: Uh-huh. (pause) Okay. (pause) And now that you think about death and dying- uh- do you look back on your life a lot?

B: No. Uh-uh.

A: Oh, you don't? Okay.

B: 'Cause the last time I was in the hospital, I don't remember things anymore. No, I was out of it for three days and didn't remember anything. And I don't remember things that I did years ago anymore. Just a few incidents comes every once in a while.

A: (pause) Okay. Um- you said to go to Heaven you pray a lot, you talk to Jesus and God- now that death is closer to you, do you feel like you're praying stronger? Do you feel like you're talking more with Jesus and God?

B: Yeah. I used to pray the Rosary, but I pray more of it now.

A: Okay. (pause) Because going to Heaven is important?

B: Oh yeah. You don't want to go to the other place. It's p- it's a place of suffering.

A: Yeah. Yeah. What are the chances?

B: What are the chances?

A: Of going to uh- going to the other place?

B: I think it's pretty good 'cause I done- been good all my life- good as possible. (coughs)

A: Uh-huh. (pause) Good as possible, huh?

B: Yeah.

A: Wonderful. (pause) Uh- when I saw you for the first time on Friday um- I sh- I shook your hand, and um- you- you realized how warm my hand is.



B: Mmhmm.

A: And um- and then you said um, “I have a cold- cold hand.” But you have a warm heart.

B: Yeah, it’s a cold hand and a warm heart.

A: (pause) You’re someone with a warm heart.

B: Mmhmm. We have all kinds of sayings like that.

A: Uh-huh. (pause) You lived a little- you lived life where you had your warm heart.

B: I lived life with uh- what come to me, I took care of it.

A: Okay. Like your mother?

B: Mmhmm. (pause) I helped with my father when he was sick and he got pain and had to go to the hospital. I took him to the hospital. And took my mother there and afterward, I come back and got her. And went home. (pause) And I used to stop and see my father every night when I went home from work- when he was in the hospital. And he gave me these little things of milk that he get with his tray.

A: Little things of what?

B: Milk that he gets with his tray and says, “Give this to my dog at home.” And so I get his all little-mil- milk things to his dog.

A: Uh-huh. (pause) So you did a lot for your family, huh?

B: Yeah.

A: (pause) Wow. That’s very good of you.

B: Well, I had to take care of my younger brothers. The two of them that are much younger than the rest of us. And then I went to work, and I didn’t know too much about my younger- youngest brother- what he did when was little. But I remember the other brother. We used to tease him a lot. And we’re happy we had a little brother in our family. Yeah, some people they don’t want ch- any children after so many years, but we thought it was wonderful that we had a little brother.

A: How much younger is he?

B: My youngest sister was six years old when he was born. So he was quite a bit younger than the rest of us.

A: Okay. How much younger is he from you?

B: Hmm?

A: How much younger is he than- than you?

B: Ten year- I would say- I was sixteen or seventeen when he was born. Oh that was the other one- I was thirteen when he was born.

A: Oh, wow. Okay. You liked how young he was, huh?

B: Yeah. It was interesting raising him.

A: You raised him?

B: No, the whole family raised him. We used to do things together. Like the na- na- learned the names of uh- the rest of his family. We used to say, "Willie, what's my name?" (laughs) And if he got it wrong, he says, "Darn it."

A: (laughs) Wow. You remember all these things?

B: Yeah.

A: Growing up with your family is something that's memorable?

B: Yeah, it is.

A: Mmhmm. (pause) Do you think about that a lot as- now a days- recently?

B: Yeah- uh- as much as I can. 'Cause after I had the last episode in the hospital, I can't remember too much anymore.

A: Okay. So these memories are important to you?

B: Yeah.

A: (pause) Okay. Memories of- any memories in particular?

B: No, not anything particular. Just regular things we used to do. (pause) Like after school was out, we had to go to Catechism lessons at- down in Cedar Road. And we had to walk all the way down there from our house. We crossed the fields to go there. And we found different things in the fields. Like I found some yellow- yellow violets. I've never seen yellow violets before. And it was so different- there was white ones and blue ones and then I found these yellow ones. (woman comes in) You want something?

Woman: Nope. Just checking on you.

B: Okay.

Woman: K. Alright. (woman leaves; door closes)

B: They make sure I'm still here. (laughs)

A: (laughs) They worry that you're not here?

B: Huh?

A: Do they worry that you're- that you're not here?

B: No, I don't think so.

A: Okay. What- what's it like being here with all the people here?

B: (pause) It's not too bad, but since we don't have enough to get extra help with it. (pause) Like the girl that works this wing has to go over to B wing, and that's around- you have to go to dining room to get to the B wing. And when she gets over there, she doesn't know what's going on over here when she's over there. When she's over here, she doesn't know what's going on over there. I told the head lady that's a- that's an awful thing because it isn't fair to the residents, and it isn't fair to the aids. And she said, "They're trying to figure out something to do about it." So- uh- so far they haven't found anything out.

A: Mmm. How do you feel personally? Do you feel like you need more help?

B: Yeah. I try to help myself as much as I can, but I can't do too much.

A: You said you uh- try to take care of others too. Do you feel responsible for other people here?

B: No. If I see someone- someone that's needing something. I've seen a girl out in the- uh- the- uh- hall with a pitcher. And I asked her, "Did you find some ice?" And she says, "No." And I told her where to look. And she come back. She said, "Yes, you got ice there."

A: Okay. K. I see. (pause) What about the other people who live here- do you feel like you take care of them?

B: No. Uh-uh. And when I first came here it made me feel like I was in a big, extended family- all these people.

A: Okay. Okay. (pause) But you said before and how about now? Is it different?

B: Yes, it's different. There aren't as many here. And I used to know every- just about everybody and who come to visit them. And- (pause) and if I happened to walk past a room and seeing something that had to be taken care of, I told the nurses.

A: Mmhmm. Okay. Okay. (pause) Okay. Um- is there anything else you want to talk about- about death?

B: No, there's nothing else I want to say about death.

A: Okay. Okay. Thank you so much for today.

B: Your welcome. I enjoyed it.

A: Good.

## **Quinn Interview # 02**

Aki (A): Okay- so- so who- who is the most important person in your life?

Participant (B): Right now it's my youngest brother. He takes care of my affairs.

A: Affairs?

B: Yeah. He takes care of my money. And then- (pause) he sees that everything gets paid and that- (pause) mmhmm.

A: Uh-huh. So he takes care of the finances?

B: Mmhmm. And he doesn't tell me anything about it. (laughs)

A: Okay. So it's his job?

B: Yeah, it's his job. And he doesn't want me to worry about it.

A: Uh-huh. (pause) Are you close to him?

B: Uh- I don't know if it's- if it's too close or not. (pause) He comes once in a while to see me. And not as much as my sister- my sister comes once a week on Fridays. (pause) And so does my younger sister.

A: Okay. So uh- tell me about your- tell me about the people in your life- the most important ones.

B: The most important is family. My uh- one brother- he didn't want me to be without yarn, so he gave me fifty dollars to buy some yarn. (laughs) Yeah. That was nice. And my youngest brother- he helped me pick out the- the yarn. And the- and he got me this blouse- and this shirt that went with it. Slacks that went with it. And that took the fifty dollars.

A: Okay. (pause) So you guys help each other?

B: Yeah. And- and my one- one brother was always my partner when we had jobs to do. Like- (pause) they- uh- my father used to go to family reunions and took to- leave two of us- uh home- home alone to take care of the- feeded them milk until they came home. And he was always my partner.

A: Oh wow. So is that the youngest brother? Or...

B: No, it's brother right next to me. The younger brother- he was much younger than me, so it wasn't- (pause) I think I was about sixteen or seventeen when he was born. So we're not too close. (laughs)

A: Gotcha. So the- the one right next to you...

B: Yeah, we always did things together. And he's the one that got me the yarn.

A: Okay. What's he doing now?

B: (pause) He's- he's going blind, so he doesn't do too much now. He used to come up once a week to see me, but now since he's going blind, they can't do that anymore.

A: Okay. Where does he live?

B: He lives in uh- Franklin County in- near the White Water- where the- uh- old White Water School used to be.

A: Okay. I- I don't know where that is.

B: Hmm?

A: I- I don't know where that is.

B: You don't? It's just down the road here.

A: Oh, okay. Okay. So not that far?

B: No, it's not very far.

A: Okay. (pause) Nice. When did uh- he stop coming?

B: When he couldn't see anymore.

A: When was that?

B: Hmm- about a year ago.

A: Okay. (pause) Okay. How did you feel when that happened?

B: I felt sorry for him. I missed him coming, but there's nothing I can do about it.

A: Okay. (pause) What- what caused the blindness?

B: Something went wrong with his eyes. (pause) Um- my brother- my mother had glaucoma, and she went totally blind. And I think he had a short- short- short- he was ta- taking medicine for that, and I don't know what else happened.

A: Okay. (pause) Huh. (pause) K. So how- how close would you say you are to that brother?

B: Oh, we always been very close. I used to- after he got married, I- uh- I felt close to his wife, and I always visited him.

A: Uh-huh. (pause) Okay. So after- uh- you and your siblings moved out of your father's place, you guys still visited each other?

B: Oh yeah. We had car- family card club once a month. And uh, even little ones enjoyed the family card club. 'Cause I went with my brother one time, and his two boys said to him, "Daddy, where are we going the next time for card club?" (laughs)

A: (laughs) So- so a car club?

B: Mmhmm.

A: Like what's that?

B: We played cards and then after dinner, we played 500. And in the evening, we'd play Euchre.

A: Okay. Wow. That's- that's some intense card playing.

B: Yeah.

A: So this is like cards like uh- uh...

B: Deck of cards.

A: Gotchya. I thought you meant like cars that you drive. But cards. (pause) Deck of cards.

B: Mmm- what do you mean?

A: No- I- I thought I- I thought I heard uh- cars that you drive.

B: No, it's cards.

A: Gotchya. Gotchya. Okay.

B: Cards that you deal with. (laughs)

A: Right. I- I figured that out. Thank you. (pause) So um- how do you think uh- how do you think your siblings- how do you think your family affected you in your life?

B: Well, we were always very close. And uh, we had uh- we had the whole family at the table for every meal. Not like they have today- the one goes this way and one goes that way. They- everybody was at the table when it was time to eat. (pause) Uh-huh. And we used to play games together. And we lived a- on a farm where the neighbors weren't that close. So it was mostly the family that stayed together.

A: Okay. (pause) So they- they were- uh- they were really close to you? They- they had to be.

B: Almost, yeah. (pause) And one brother- he lives down in Florida in the winter, and he lives up here-

here in the spring and summer. And he comes and see me a couple times a year.

A: Mmhmm. (pause) That's nice of him.

B: Mmhmm. And my one brother lives up in Illinois, so- near Rockford, Illinois, so he doesn't get to see me too often. (pause) But I write to him every- a lot of times. I keep him informed about what the family's doing and what I know about the family.

A: Uh-huh. Wow. You guys are one unit.

B: Hmm?

A: You guys are just one together. There's so much togetherness.

B: Mmhmm. He's the only one that lives that far from us. Others live right here.

A: Okay. Wow. It's- it sounds like uh- your family i- is the most important thing.

B: Yeah, it is.

A: Okay. Okay. (pause) And- and so they affected you a lot?

B: Yeah.

A: Could you talk about how they affected you? What kind of person you are because of them?

B: (pause) Mmm- I don't know. My youngest brother- my father called me his second mother. So (pause) the other ones w- we- we- we were always together.

A: (pause) Mmhmm. Could you talk about the time that you uh- you moved out of your family's house when you were young?

B: Well, then my father got me a job doing housework, and I had to stay there- stay- I lived right in there with them. And uh, I did that for eleven years. And then I got a job at- C- Cincinnati Gas and Electric, and I moved back home then. And my younger brothers were still at home. And so I got to know them a little better.

A: Okay. (pause) Because uh- you said you weren't really close to them before 'cause they were really young.

B: They were t- too much younger than me- yeah.

A: Uh-huh. But you moved back with them?

B: Yeah.

A: And you got to know them better?

B: Yeah.

A: K. (pause) How was that?

B: (pause) Well, they were still in high school when I come back I think. Mmhmm. And the one went to the service. And the other one who gra- graduated from high school, he went to college. And the one in the service, when he come back home, he went to college too. They both have college degrees and had good jobs.

A: Alright. (pause) Did you relate to- relate to them well?

B: (pause) Mmm- I don't know. They were so much younger than me that I di- we didn't uh- get to know each other that much.

A: Okay. K. (pause) They're still a part of the family though?

B: Yeah- still part of the family.

A: Okay. (pause) Okay. So- so you were working for the Cincinnati Gas and Electric, and that's when you moved back to your parents' place?

B: Yeah.

A: Okay. Okay. So you- you were- uh- where- where were you living before?

B: I lived right in where- where I did housework. (pause) And then when I got the job down in CG&E, I- I moved back home.

A: Mmhmm. (pause) Okay. How- how did you feel moving back home?

B: Uh- it was okay. I was comfortable going back home. And mom said to me- once I was upset about something- she said, "You always got a home here with us." They make me sure that I didn't have to worry about where I was going to live.

A: Okay. How did that feel to you?

B: I felt fine. (pause) I knew I had a home to go to.

A: Uh-huh. (pause) That- that's nice. That sounds really nice.

B: Yeah, I stayed with my mother until she died. And then I got a- uh- went to a retirement home. I stayed there five years, and I got sick. And that's when I come up here.

A: Oh you were in the retirement home before that?

B: Mmhmm. Yeah, it was really nice there. I could do what I wanted to do. And I went on trips and-



and- uh- we went out to eat and stuff like that. (pause) And once a week they took a bus ride in the- in the afternoon for us to go around the city. And one time I took them out to see my- uh- church that I went to because it's so pretty. And in there it's got all these pictures on the ceiling. And I thought they would enjoy that. So I took them out there. And coming back home, I took them place that- place where I lived. And I showed them the one room school that was on that road. And later one of the ladies said, "When are we going to do that again?" (laughs)

A: Huh. (pause) So these memories are pretty- uh- lively.

B: Oh yeah. Yeah, I enjoyed staying at the retirement home.

A: Okay. So who did you go on trips with- the people in the retirement home with you?

B: No, I went by myself most of the time. And I made friends on the tri- trip.

A: Oh. Okay. Huh. Huh. So you made friends with the- uh- the people at the places that you went?

B: Mmm- that went on the tour with me, yeah.

A: Oh. Gotchya. Okay. (pause) Nice. Um- so were you close to your family- uh- back in the retirement home?

B: Uh- that's- that's after my mother died. And uh- (pause) I wasn't too close to them. I used to go visit my brother all the time.

A: Uh-huh. Which brother was that?

B: The one that was next to me. Yeah, we were pretty close.

A: Mmhmm. What does it mean when you say close? What do you mean by that?

B: It means that we're about- we were- (pause) I can't explain it. I'm sorry I can't explain it.

A: But- but something-uh- that you can't describe- something that...

B: Yeah.

A: Okay. Okay. (pause) How do you- uh- express to him how- how he made you feel- how close he is to you?

B: No, we never did talk about it. He used to tell me, "You visit with my wife, and I'll- I'll see you later."

A: Okay. Okay. (pause) So you guys never talked about it?

B: No, we never talked about it.

A: Okay. (pause) But you cared about him?

B: Yeah.

A: And he cared about you?

B: Yeah. He gave me fifty dollars to spend on yarn.

A: That's- that's great. That's so nice of him.

B: So- so he was trying to make sure I didn't get ri- get tired of sitting by myself.

A: Uh-huh. (pause) Could you- uh- tell me a story about- uh- your family- something that- uh- something that talks about the closeness you had with them?

B: Oh- well, we always played games together. And- and played cards even though we didn't get cards- I used to play cards at home. Yeah, we always- always had something to do together.

A: Nice. And this was- uh- even after you and your siblings moved out?

B: Uh- yeah, they got together once a month even though I couldn't go all the time.

A: Mmhmm. Okay. So your family's still close to you even after you moving out.

B: Mmhmm.

A: (pause) How do you feel about that?

B: (pause) Well, it- it's just naturally I think. Naturally you feel close to your family. Or is that something I just feel?

A: I don't know. But you feel it?

B: Mmhmm.

A: Okay. (pause) Okay. And they're the most important people?

B: Yeah.

A: (pause) Okay. Um- so last- uh- when did I see you last time? That was- uh- uh- Sunday- Sunday. Um- we talked about death and dying?

B: Yeah.

A: And- and you talked about- uh- um- you recently had your birthday, and um- you'd been thinking about death a lot more than before?

B: Yeah.

A: Before you weren't really thinking too much about dying?

B: No. Now I'm thinking more about it.

A: Right. (pause) Um- I was wondering if there's a- if there was anything- any difference between- uh- um- I'm sorry. I'm wondering if there's a difference in the way that you think about your family from the time that you thought about- you didn't think about death and the time that you do think about death.

B: Mmhmm. My- my brother and I went and made all the funeral arrangements for me and got that all taken care of.

A: What was that like?

B: Well, it wasn't- it wasn't too bad. We just talked about what we wanted to be done at that time.

A: Mmhmm. (pause) Mmhmm. So he was helping you in making- uh...

B: Funeral arrangements, yeah.

A: Wow. (pause) K. How did you feel when that was happening?

B: Feeling what?

A: Anything. What were you feeling as- as he was making those arrangements?

B: I was glad to get to- get to make them myself, so when I- when I die, they don't have to try to figure out what I would want. (pause) What I would want. (pause) And my brother wrote it all down, so he keeps the record of what I want.

A: Mmhmm. How- how did he- uh- how did he look as he made all- all these arrangements?

B: Uh- well- he forgot about it afterwards. That was it.

A: Okay. Okay. I see. Does- does- has the way that you think about your family changed since you started thinking about death?

B: No. Uh-uh.

A: It hasn't?

B: I haven't talked to them about it. My- uh- one sister-in-law- I said something to her, and she said, "Don't talk about that. We- we're going to live here a long time yet." So they don't think I should die soon.

A: Why do you think that is?

B: Well, she- she's got so much to live for, and I don't have no plans of- for the future. So- (pause) she's got her family, and she wants to see them- uh- what her grandchildren do and...

A: Uh-huh. So- so when you guys were talking about death- um- was she concerned about your dying? Or was she concern about- concerned about her dying?

B: She- she was more concerned about her- she said she didn't want to die yet. But she was okay with me telling her I wanted to die.

A: Okay. (pause) She was okay with that?

B: Mmhmm.

A: Okay. (pause) Have you had any other reactions from your family about the dying process?

B: No. Uh-uh.

A: Okay. (pause) So how is your relationship with the family changing now that you are in nursing home?

B: (pause) Well, I don't get to see them as much as I used to. I used to go to card club with them. But since I'm here, my one- one niece used to take me until I got- it got to be too late for me to come home. And then I- they stopped taking me there. And I couldn't stand all the little ones. (laughs)

A: Little ones?

B: Yeah, little ones. They're- my- uh- um- brothers' and sisters'- they had grandchildren they brought to fa- family card club. And they were all running around, and I tried to figure out one time which one belonged to who, and I couldn't figure that out.

A: They're so many of them?

B: Yeah. (pause) I couldn't figure out which one belonged to what family.

A: Wow. Wow. So many children?

B: Mmhmm.

A: Grandchildren.

B: Yeah. My mother had thirty-three grandchildren when she died.

A: Thirty-three grandchildren?

B: Yeah.

A: Wow. (pause) Wow. When did your mother pass away again?

B: In 1991.

A: Okay. Okay. I see. Huh. (pause) What was her death like?

B: Well, I- I didn't realize she was- uh- dying until they called me and told me that she had died- passed on. But then- then when I think back when I was here, and they told me she ju- just went during the night. And- and she didn't want to drink anything. And then- uh- they- they- they- uh- sort of told me that's what's going to happen. But I didn't realize that until they called me and said she was gone.

A: K. (pause) How did you feel when they made that phone call?

B: Uh- not too bad. All I knew- I had to call all my brothers and sisters and let them know. 'Cause we had to make arrangements for the funeral and that. And we had just planned her card club- we were all together. And we decided what- what we were going to do.

A: Okay. And your mother was the first to be included in that? Is that right?

B: The funeral arrangements? No. She was the- she was the one that was dead, and the rest of us had to- different jobs to do. Like who would be palm bearers- where the- the grandsons were palm bearers. And the- and the chi- the- uh- little girls- they brought up the uh- Eucharist and that- prep- pa- ra- for the mass. And uh- (pause) and we went to the funeral home the night before, and had people come in and talk to us- that knew- knew her. And the next day we had the mass at the church down Cedar Road, and they buried her right out in the court- courtyard- graveyard behind the church. My father was buried there when he died. And he- he bought a lot for him and her and me. So we're all be buried together out there. And my brother bought a lot right next door- right next to us.

A: Wow. (pause) So even after death, you guys will- will be together.

B: Yeah, we'll be together- four of us- just the ones that were- (pause) 'cause the other ones- my older brother- he died and he's buried out in Indiana. And uh- my brother up in Illinois, I imagine he's making arrangements up in Illinois. I don't know. But my o- one brother said he- he got a- he made arrangements when his wife died, and he's going to be buried there too- at a church in Cincinnati.

A: (pause) Is it important for you to be uh- staying together with your family- in the- in the funeral? I'm sorry. In the- uh- the graveyard?

B: No, it just happened that way.

A: Oh. Okay. (pause) Okay. (pause) It doesn't feel- uh- you don't feel anything about staying together with your family in those places?

B: No. Uh-uh.

A: K. (pause) Okay. What kind of- um- story do you think you want to leave behind to the ones that are going to live after your death?

B: Well, I- I wrote a book after my father died. I wrote a b- uh- a thing about his life because I knew some of the grandchildren didn't get to know him too well. And I wrote- wrote that up, and they keep it. And uh, I wrote it- another one about how-how we- what we did when we were little and the things we used to do and play. And my brother made a- a story out of it and gave uh- each family two copies of the story. So they- they have something to read because my- some of my nieces and nephews- they read it and said they wanted to get- read more of it. So they were very interested in what I wrote.

A: What- why did you write it in the first place?

B: Why did I write?

A: Mmhmm.

B: When my father died, I realized that some of my nieces and nephews didn't get to know him too well, so that's why I wrote that. But I don't know why I start writing about things we did when we were little. I just started to write. I- I write pen-pal letters, and I love to write.

A: Uh-huh. What kind of things do you like writing about?

B: Well, I read the letters they send to me, and- and- uh- take it from there- whatever they happened to have in there, and then I remember something that'll go with it- a story that go with it.

A: Uh-huh. (pause) Okay. Was it important to you to be writing those?

B: Yeah. 'Cause I di- didn't make too many friends outside. And that way I had a lot of friends that way.

A: What way? By writing and...

B: Yeah, I had the pen-pal friends. (pause) They're from all over the country.

A: Are they?

B: Mmhmm.

A: Do- do you still write to them?

B: Yeah, but right now I can't do it too much anymore. I got too nervous.

A: Nervous?

B: Yeah, I was in the hospital. And when I come home, I couldn't do too many things anymore.

A: Okay. (pause) What were you in the hospital for?

B: (pause) Mmm- I don't know right- I was out of it for a couple days. But I don't know what it was all

about. But I know I didn't remember anything about it. So it's still puzzling me what I was in there for. When I come out, had- had this- uh- uh- infection in my bowels. And that took me down some too.

A: Oh. I'm sorry. (pause) It was painful?

B: Yes, it was painful at first. But after a couple weeks, it was better. It didn't last too long.

A: Uh-huh. (pause) K. Uh- let's go back to that- the writing piece a little bit. Um- so you were writing about your father?

B: Yeah, and things we did when we were little.

A: Mmhmm. (pause) Those memories?

B: Yeah.

A: Okay. (pause) Last- uh- last Sunday you were talking about how you were trying to remember those because nowadays you don't really remember too much.

B: No. Nowadays I can't remember too much. Since I had that little stunt in the hospital.

A: Yeah. (pause) Uh-huh. Uh- let's go back to that question of- uh- what kind of story would you like to be leaving behind after your death?

B: The stories I wrote is enough to leave behind. And they- then I know that my nieces and nephews appreciated that I did something like that.

A: Uh-huh. Is it important to you that they feel- uh- that they appreciate what you've been doing?

B: Yeah. (pause) In fact my one niece says to me, "You keep on writing."

A: Uh-huh. (pause) What do they mean to you when they said that?

B: They meant I should keep on writing what was I was writing about. They li- they think it's interesting.

A: But how- how did you feel when you- when you heard that?

B: That I'd- it did something that it'll go down in history with the family.

A: Nice. (pause) And was that something important?

B: Yeah, they have something to remember me by.

A: Uh-huh. Uh-huh. (pause) So it's important for you to be remembered.

B: Yeah.

A: (pause) What would you- uh- like them to- uh- remember about you?

B: Things I did with them years ago when they were little. I use- one family used to come out on Saturday. I used to take them for a walk in the woods. And whe- when we got back from woods, we had soft drinks and- and they remember that.

A: Uh-huh. (pause) Uh-huh. So things that you did with them?

B: Mmhmm. At Christmas time, I made- we did cra- craft things for- with them and...

A: Mmhmm. (pause) And these were happy events? Sad events?

B: Mmhmm.

A: (pause) K. So you want to- uh- leave the family legend behind?

B: Yeah. Leave them the history of the- what we did. And (pause) my two younger brothers thought when daddy and momma got married, they lived right on the farm. And I said, "Oh no. They lived in a city for a while." They lived- uh- uh- daddy worked for assisted and nursing, and we lived right on the property. And then when it- they decided- 'cause sisters cut their pay too much, they all just decided to quit at the same time. And uh- that's when my father built the house, and- uh- we lived in that for almost a year before we went up to the farm.

A: Mmm. (pause) Okay. K. So when you were working for uh- city- uh- for the Cincinnati Gas and Electric, that was- uh- that was when your family was still living in Cincinnati? Or...

B: No- after they were on the farm.

A: Okay. Okay. (pause) Okay. Okay. So after- after you pass away- um- you want your little ones to remember about what happened?

B: Yeah, the things I did with them.

A: Uh-huh. Kind of like how you wrote- uh- about your father- so you could tell those little ones?

B: Mmhmm.

A: Uh-huh. So the legend continues on.

B: Yeah.

A: Is that right?

B: Yeah, it's all written down on paper. And my brother typed it up with his computer- (pause) made a story of it.

A: Huh. (pause) What do you mean story? So he- he- did he pri- print it out? Or...



B: Oh yeah. He- uh- can- read it- uh- typed it out on his computer and made pages and pages of it.

A: How many pages?

B: I don't know how many exactly. But he- he didn't show me the complete thing.

A: Okay. K. (pause) How long did you write about your father?

B: Uh- I did that right after he died. It didn't take me too long. I- the things I thought that they should know about their fa- their grandfather.

A: (pause) Do you- uh- do you want to write about your own life now that you are close to death?

B: No.

A: No. Okay. Why not?

B: Mmm- I can't write anymore.

A: Okay. Do you want someone else to write about you?

B: No.

A: And why is that?

B: I don't think anyone wanted to do that.

A: (pause) Uh-huh. (pause) Could I ask why?

B: Mmm- I don't know. I just don't think anybody would want to write about me.

A: Hmm. (pause) Okay. Hmm. (pause) You don't know why?

B: No. (pause) I hope this is making a lot- a lot up for your study.

A: Yeah. Yeah. No. This is your story.

B: Mmhmm.

A: (pause) Okay. But you want- you want those little ones to remember about- about you?

B: Yeah. (pause) They remember the things we did when they were little. (pause) One niece that- she was in the Girls Scouts, and she had to do- learn how to do six different kinds of embroidery stitches. And the- her mother got her a pair of pillowcases. And she- she learned the different stitches. And then showed them out at- uh- the- the Girl Scouts and got her badge for doing that. And then she never finished them. And one time her mother was going through the cu- cupboard and found them. And she gave them to me and said, "You finish these, and I'll give them to her for a present." (laughs) So I

finished them, and she gave them to her for her birthday.

A: Wow. (pause) So it was a birthday present?

B: Yeah.

A: Oh. Okay. (pause) Wow. How did you feel doing that?

B: Eh- I feel o- okay about it because I didn't realize she hadn't finished them, so I finished them.

A: So it was a collaboration?

B: Mmhmm. She did part of it, and I did part of it.

A: Right. (pause) Very nice. And you want that to be remembered.

B: Yeah, she got it for her birthday.

A: Uh-huh. (pause) What does it mean when they remember stories about you?

B: I don't know.

A: You don't know?

B: Know what?

A: (pause) What it means- uh- what it means when they remember about you and your stories?

B: I don't know.

A: Okay. (pause) Okay. I think that's it.

B: It is?

A: Is there anything else you want to say about your family and what it means to be passing away?

B: No, we've always been close. And e- even when they- one of them passes away- uh- you still feel like they're part of the family. My- uh- one sister passed away shortly after mom passed away. And it just feels like she shouldn't have been gone yet. But she had so much wrong with her that it was a blessing that she went. And my brother- he was in a coma for nine months. And he didn't know anything, so he- he was- so I was happy that he passed on. Because he just laid there and couldn't do anything for himself. And my one brother insisted I go see him, so I went to see him- in that condition. And I thought, "Oh, that's terrible- making him live like that."

A: Okay. So many of them you saw in their beds, and you didn't like how you saw them?

B: (pause) Didn't like how I saw them. Uh- you mean when they were sick like that?

A: Right. Right.

B: Yeah, I didn't think it was right to keep- try to keep him alive when he wasn't able to do anything for himself. He just laid there and- uh- and- and- had someone had to take care of him.

A: One of the sisters you said- uh- sh- shouldn't have been gone. What made you say that?

B: (pause) Oh- let me see. She was young when she went. So- (pause) but I thought after all she was so sick, just let her go.

A: K. How old was she?

B: Sixty-five. (pause) Now that I'm eighty-five, it seems so long ago.

A: Okay. (pause) So your sister was sixty-five?

B: Yeah.

A: When did she pass away?

B: In 1997. (pause) 1996- I came here in 1997- (pause) shortly after she passed.

A: (pause) So about- uh- sixteen years ago?

B: Mmhmm. It'll be sixteen years in January.

A: Okay. K. You remember all these dates?

B: Yeah. (pause) The doctor that operated on me he said- uh, "Let's see what the date was." And I told him right now. And he says, "You remember better than I did."

A: (laughs) Wow. (pause) You're a smart woman.

B: Hmm?

A: You're a smart woman.

B: Oh, I don't know.

A: (laughs) You memorize well though.

B: Yeah. (pause) Yeah, I memorize all these different prayers we had. I can still remember praying them in church, and- and I pray them now.

A: Uh-huh. Uh-huh. (pause) What do you pray for?

B: (pause) To be closer to God.

A: Mmhmm. (pause) You want to be closer to Him?

B: Mmhmm.

A: Okay. Okay. How many of your siblings are still here?

B: Uh- there's just two of them died. The rest of them are still here. There's six of us.

A: Oh. Okay. Okay. Alright. So- so your sister who passed away at sixty-five and your brother who passed away?

B: Yeah, he was seventy-seven.

A: Mmhmm. K. K. Do you miss them?

B: Not really. When I first came here and seen a car that looked like my sister's, I thought, "What's Helen doing coming to visit me here." And I thought, "Oh no. She's no longer here."

A: Oh. Okay. (pause) You don't miss them?

B: No. (pause) I was never that close to them. My older brother- he was extra smart, and when I come along, I couldn't do the things he could do. And the teacher- the teacher says to me, "Why can't you do what your brother did?" I said, "Well, I'm not my brother."

A: (pause) Huh. (pause) You're not your brother?

B: Hmm?

A: You said you're not your brother?

B: Yeah. He could do things I couldn't do, and I could do things he couldn't do.

A: Mmhmm. You guys were different?

B: Mmm- yeah- different things.

A: Okay. (pause) Okay. Well, thank you so much. I- is there anything else?

B: Not that I know of. Unless you know something.

A: No, I've- I- I asked all the questions that I wanted.

B: Okay.