

Death Anxiety in Elderly Communities (Retirement-Nursing Homes): Participant Observations, Interviews, and Analysis

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Fascinating are projects that explore microcosms in society which remain for individuals largely unknown and hidden until changing personal circumstances render those microcosms visible. The circumstances with which this paper is concerned are advanced age and declining health; the microcosm is that of a Metropolitan Milwaukee retirement-nursing home. The purpose of this paper is to investigate via interviews conducted with staff and residents of and participant observations made at this retirement-nursing home the levels of death anxiety felt by members of the latter group. With consideration of subjects' emotions regarding their surroundings, I concluded that (a) elderly individuals living in the facility experienced greater death anxiety than those residing in personal residences and that (b) there existed within the confines of the retirement-nursing home opportunities for staff members to make environmental improvements so as to limit individual experiences with death anxiety.

Fascinating are projects that explore microcosms in society which remain for individuals largely unknown and hidden until changing personal circumstances render those microcosms visible. The circumstances with which this paper is concerned are advanced age and declining health; the microcosm is that of a Metropolitan Milwaukee retirement-nursing home. I first contemplated the significance of retirement-nursing homes after making frequent stops at one such facility in Wauwatosa, Wisconsin, to donate books and visit my grandfather, a resident at the facility. There, I noticed a deep undercurrent among residents, a serious yet largely unexpressed concern, that of death anxiety. Such is the topic of this paper. Building on works by Jeanie Kayser-Jones (2002) and Judith Barker (1999), who have investigated into the lives of elderly persons and their experiences with death, it demonstrates that elderly individuals living in this retirement-nursing home experienced greater death anxiety than those residing elsewhere, namely personal residences. It also calls for further applied anthropological research into retirement-nursing home communities so as to aid in limiting death anxiety felt among retirement-nursing home residents.

BACKGROUND TO RESEARCH:

It is a classic American adage that there are but two certainties in life, death and taxes. This adage, while reflecting American attitudes about aspects of our biology and society, hints at widespread concerns regarding end of life. This is due largely to the fact that death, contrary to taxes, is a topic rarely discussed in open forum. Nevertheless, like the topic of taxes, that of death is often forefront in peoples' minds; hence, the great lengths to which we go to hide and exclude death from daily social life. To illustrate this American tendency, I offer our

affinity for transferring the dying from personal residences to hospitals. Elderly individuals we tend to transfer from personal residences to retirement-nursing homes specifically (Cohen 1998). Both have the effect of banishing from public view the natural inevitability of aging and dying, thereby furthering our present culture steeped in death denial and corresponding hedonistic, “here-and-now” attitudes towards life (Aries 1974). Furthermore, we have redefined the narrative language of death from that of a sacred, spiritual happening to that of a biological and technical process (Geertz 1973). These trends reflect a culture increasingly fearful of dying and engaging in death-denial. Our preoccupation with youth and beauty, perpetuated by the media and plastic surgery, cling to an illusion (Wong 2009), yet they do nothing to halt the inescapability of death. As Max Weber (2005) identified, capitalism in the West has shaped our culture. Its influence extends to our views of death as something that is meaningless or indicative of failure and tragedy (Weber 2005). As a result, death has been remanded to the realm of repressed human experiences.

There are many factors in the advancement of American society that have perpetuated our view of an “invisible death” (Aries 1974), in which experiences with death are kept private and removed (Aries 1974). Distancing ourselves from death is due, at least in part, to societal changes in who dies (from the young to the elderly), changes in when we die (from the premature to the post-mature), and changes in how we die (from the sudden to the slow) (Belsky 1999). The most influential development has been industrialization, which continues to increase living standards through better food production, better housing, more efficient sanitation facilities, and education (Aries 1974). Technological advances in medicine have also prolonged life through sterile hospitals, immunizations, and surgery.

In our culture, language erects a great force towards furthering establishment of “invisible death” (Aries 1974). Talking about death is often avoided. In fact, there seems to exist an aversion to the word “death.” Quite often in lieu of said word, phrases such as “passed away,” “passing on,” “end of life,” or “loss of loved one” are used. This “invisible death” (Aries 1974) is further reinforced by the media, which frequently portrays death abstractly and superficially. Movies often romanticize individual battles with death, and cartoons regularly make death seem comical – how many times have we seen an anvil dropped on Wily E. Coyote by the smirking Road Runner? All of these factors, though admittedly incomprehensive, have led to cognitive denial of the natural occurrence of death through emotional repression and behavioral passivity. We hide our feelings not just from others but from ourselves so as to continue the charade of being able to control all aspects of our daily lives. We have become passive observers of death in our culture by allowing professionals, i.e. physicians and funeral directors, to process dying and dead bodies (Aries 1974). Removing us from contact with the dying and the deceased reinforces our lack of social compassion, leading many to feel isolated when dealing with grief over loss of a loved one (Belsky 1999).

This trend in our culture, of denying death, leads to great amounts of death anxiety to be experienced by individuals. Fear of death has been rated as the most common fear among Americans (Wong 2009). It stems from fear of the unknown, fear of finality of death, fear of cessation of life, fear of losing loved ones, and fear of pain and suffering (Belsky 1999). The anxiety resulting from these worries is an experience of heightened tension due to the threat of danger. It is theorized by animal behaviorists that all animals experience anxiety, serving the purpose of alerting one to possible danger (Becker 1973). But how do we explain anxiety which fails to serve such a purpose, cropping up at times when it is unbeneficial to the individual? Psychologist Janet Belsky (1999:368) defines death anxiety as “the thoughts, fears, and emotions about that final event of living that we experience under more normal conditions of life.” Sigmund Freud (1953) postulated that people experience thanatophobia, or fear of death, due to the unknown and unresolved childhood issues that individuals feel they cannot face and acknowledge. In *The Denial of Death* (1973), Ernest Becker proposed that death anxiety is people’s most profound source of concern. He states that the experience is so intense that it can generate numerous fears and phobias to the point where much of peoples’ behaviors are attempts at denying death and managing their anxiety.

POTENTIAL DIFFICULTIES AND FORESHADOWED PROBLEMS

Many are the variables that influence levels of death anxiety. These include age, environment, religion and/or spirituality, illness, and self-identity. It is hard to measure death anxiety within a population because it resides in the realm of the intrapersonal. The symptoms of a person experiencing death anxiety are also extremely hard to measure due to the repressive nature of our culture with regard to such feelings. In some hospice settings, care workers are required to watch for trembling, restlessness, sweating, nausea, insomnia, irritability, and increased heart palpitations as indicators of death anxiety (Singh 2003). Residents, in some cases, are treated with anxiolytics and antidepressants and are asked to engage in relaxation techniques such as meditation (Singh 2003).

The very nature of the retirement-nursing home is predisposed to frequent deaths because of its residents’ advanced age. Therefore, it would be reasonable to question if the elderly residing in such a setting experience a heightened level of death anxiety. What variables heighten death anxiety; do mature age and the retirement-nursing home environment enhance degrees of death anxiety experienced? These are the questions that drove my research, a reasonable pursuit considering that approximately 25% of our population is elderly, meaning 65-years-of-age or older, and that half of those individuals will die in a retirement-nursing home (U.S. Census Bureau 2009). In addition, due to aforementioned trends being deeply seated in our culture, many of us are likely to end up in retirement-nursing homes.

Given their advanced ages and the fact that they are either in declining or fixed states of poor health, retirement-nursing home residents are forced to face the reality of their impending deaths as well as the impending deaths of fellow

retirement-nursing home residents. Facing the reality of death is a natural part of life that all creatures must experience. For the reasons stated above, the reality of death is, in retirement-nursing homes, ever-present, as is the realization that individuals in such facilities are left with dwindling time to live. The foreshadowed problem addressed in this paper is the affect that impending end of life has on death anxiety felt by residents of a Metropolitan Milwaukee retirement-nursing home.

SETTINGS AND METHODS

Methods in carrying out research for this project included participant observations and interviews. Participant observation was done in two parts; first, observation of the retirement-nursing home's common areas was conducted to see how often the topic of death was discussed or avoided by retirement-nursing home residents and staff. I add here that the facility at which I carried out research was a private establishment with religious affiliation to the Lutheran faith located in Wauwatosa, Wisconsin. Second, observation at frequent funerals and wakes held at the retirement-nursing home was also conducted. It was anticipated that this would offer insight into how members of this "dying" community accepted or denied end of life as well as make visible specific tactics used by staff to manage death anxiety felt by retirement-nursing home residents. These observations made at funerals and wakes at the retirement-nursing home I compared to those which I made outside said setting over the course of personal experience.

Interviews were conducted during the latter half of research with retirement-nursing home residents and staff, at their convenience. Interviews were handled delicately, as from personal experience, most Americans, not only our aged, often have a hard time discussing death. Three groups of individuals were interviewed to get a broad measure of death anxiety in the retirement-nursing home community. Group number one consisted of eight elderly retirement-nursing home residents, chosen for their ability to describe experiences with death anxiety in this setting. Introductory questions requested disclosure of background information such as their ages and how long they had been residents at the retirement-nursing home. This information provided a context in which I could begin to analyze levels of death anxiety experienced in the environment. Group number two consisted of three staff members at the retirement-nursing home. They were interviewed to gather staff observations and perceptions relative to instances of resident death anxiety. Background information requested of these interviewees included their ages and their durations of employment at the facility. This information provided insight into how familiarized employees were with the setting and the amount of time they have had to observe the residents and their experiences with death anxiety. Lastly, group number three consisted of three elderly individuals residing in personal residences. Group number three acted as a comparison group to group number one.

Interviewees of each group were asked many of the same questions, as I am interested in all individuals' perceptions of death and the levels of anxiety experienced when contemplating the topic. However, each group was asked separate questions specific to their role or setting (Appendix A). Residents of the retirement-nursing home were questioned as to their personal experiences and feelings on life in such a facility. As members of a retirement-nursing home, I presumed they could offer unique perspectives into the setting and the reactions and emotions it tends to evoke. Staff members were questioned as to their observations and perspectives of the facility's residents. They also were questioned about their personal perspectives on death. These queries were made to ascertain if death anxiety in a retirement-nursing home affects staff as well as residents.

All interviews were conducted privately and as respectfully as possible for the simple reason that they dealt with the sensitive issue of death. Permissions was granted by the retirement-nursing home's regulators and by the participants themselves. Please note that participation was voluntary. More residents chose not to comment or be interviewed than those who did agree. I can only speculate that preferring not to discuss the matter of death was in itself an expression of death-denial, but, as I did not press the issue, I have no definite answer to the question of *why* most residents approached chose not to participate.

Interviews were audio recorded so as to maintain focus on the individual interviewed and to allow for notation of observations made pertaining to interviewee expression, demeanor, and overall behavior. Upon completion of interviews, audio recordings were transcribed in coordination with notes taken. The goal of transcribing audio-recorded interviews in consort with notes taken was to provide myself with the greatest context possible and therefore allow for later accurate analysis of what took place.

As introduction to the facility in which my subjects lived or worked and at which I carried out all participant observations and interviews, I include here an excerpt from my fieldnotes:

Location: Retirement-Nursing Home Hallway and Nurses' Station:

Walking down a hallway approaching the nurses' station, I am reminded of an abandoned parking lot where no longer functional vehicles are dropped off before being crushed or designated to the junkyard. The hallway is very utilitarian in appearance. The lower halves of the walls are painted a dusty rose, and the upper portions are taupe. The hallway is lined with doorways to rooms, some of which are resident apartments, about every ten feet. Between each doorway hang poor imitations of art, most of them depicting nature scenes and bouquets of flowers. The area is lit from the ceiling with rows upon rows of fluorescent lights that emit a low hum and in no way flatter the walls. They are so bright that they would compete, and perhaps best, the sun on a cloudless day. I wonder who designed the color scheme and decoration for this facility and what mood they were trying to convey. The clash of things that are "medical" and

“homey” does not seem very comforting to me. There is a penetrating smell of body odor, formaldehyde, and bleach. I worry that the smell will attach to me since even the bleach cannot seem to eradicate the other odors. My ears are assaulted from multiple sounds. TV or radio dialogue emits from most of the resident apartments, and a repetitive buzz resonates, corresponding with a flashing light on the wall next to a doorway. Telephones are ringing at the nurses’ station, and a nurse is loudly barking orders at an aid. I wonder if there is any area in this facility where one could find quiet. The temperature is stifling warm like a Petri dish, which is surprising since lower temperatures would hinder bacteria growth and transmission of germs. A nurse’s cart is parked outside one of the resident doorways. The cart is a dull gray metal and very large. The top of the cart is laden with gauzes, syringes, and pill cups. The paraphernalia atop the cart leads me to wonder what sorts of instruments and medications are hidden under lock and key in the numerous drawers that compose the cart. On the other side of the hallway is an elderly woman sitting in a wheelchair slumped over to one side. It is disconcerting. I question upon seeing her whether she is dead or just sleeping. She has a sparsely populated head of white wispy hair, is dressed in a ratty light blue bathrobe, and has pink fuzzy slippers on her feet. Attached to the back of the wheelchair is a metal tank with a hazard symbol in red and yellow. From the top of the tank snakes a clear tube that passes over the shoulders of the woman and into her nose. It is hard to look at her and not feel some emotion – pity, concern, avoidance. I feel all three and do not know whether to ask if she is ok or to just walk by and let her be. Further in the background, at the end of the hallway, is the nurses’ station. The large wooden station dominates the junction of the hallways. On the counter, a lone potted green plant sits amid the disarray of numerous papers, notes, and charts. The area reflects high activity and documentation. The environment is a clashing of two worlds – a faint “homey” atmosphere and the efficiency of a medical facility. It is my opinion that these two worlds do not merge cooperatively and, in truth, highlight the difference between the two and bring into glaring light the lack of a cohesive atmosphere.

MAIN EMPIRICAL FINDINGS AND ANALYSIS

Following interviews conducted with staff and residents of and participant observations made at the above-described Metropolitan Milwaukee retirement-nursing home, I arrived at eight conclusions regarding levels of death anxiety experienced by said facility’s residents. I list those here and elaborate on each below. Finding number one - many retirement-nursing home residents had a difficult time facing death; therefore, a good number chose to avoid mass gatherings predicated on the topic of death, i.e. funerals and wakes. Finding

number two – all interviewees experienced heightened stress when deliberating on the topic of death. Finding number three – elderly individuals residing in personal residences appeared to cope better with aging and the inevitability of death. Finding number four – many elderly chose not to contemplate end of life. Finding number five – religion and spirituality appeared to lessen degrees of death anxiety felt. Finding number six – individuals in poor health feared death more than those in good or moderate health. Finding number seven – environment influenced degrees of death anxiety experienced. Finding number eight – those living in the retirement-nursing home expressed aversion to being there as well as a perception that one’s residence in such a facility contributes to his or her death anxiety.

Finding 1: Many retirement-nursing home residents had a difficult time facing death

While observing a funeral at the retirement-nursing home, I was focused on the prayers led by the preacher because it was obvious he was trying to relieve the fears of the residents still living. I came to this conclusion after listening to him speak of death not as an ending but as a new beginning – to a new life in heaven. He also spoke of having faith and strength to continue on until those present also passed, but with a hopeful incentive of seeing those loved ones again. I could definitely see why the preacher would include such passages in his sermon. It appeared to reassure the elderly in attendance that they had a place assured in heaven with continuation of consciousness, that there was no reason for them to be afraid, for the Lord would protect them and care for them when they arrived. It assured people that there was life after death in heaven and that they were welcome there. At this point in my observations, there appeared to be a look of desperation on many faces, almost as if what the preacher said had to be true, for life after death in heaven was their last resort at continued existence.

The preacher continually linked the concept of death with those of remembrance and rebirth. I think this originated from a desire to provide comfort as well as hope for an afterlife. What I could largely gather from my participant observations was that a measure of death anxiety was not something that could be ascertained solely from said participant observations. With death anxiety being such a personal emotion, many seemed to restrain the majority of their feelings and fears. I believe this confinement of reactions is a consequence of our culture that does not assert emotional responses (Belsky 1999).

After the funeral, I spoke with a church volunteer and inquired as to how many times a year memorials were held at the retirement-nursing home. She replied, “[a]bout two or three times a year depending on the number who pass. If there is a lot who pass away, then we will hold three. They are for the families of the residents who passed away. And friends of course.” I then asked, “[h]ow many residents usually attend.” She replied, “[u]sually, a full house, around thirty. It changes every time. Some, not many. You know at this time, around dinner, they may not want to move around too much. Also it can be hard for

them. To come to this type of service for the departed – for some it is too hard.” Her response demonstrated that while many residents chose to come and pay their respects for the departed, many also did not. Her recognition that for some it was “too hard” revealed that many of the residents had a difficult time facing death and chose not to add to their anxiety by avoiding mass gatherings predicated on the topic of death.

Finding 2: all interviewees experienced heightened stress when deliberating on death

All interviews provided insightful data and captured significant differences in how people viewed death and the stress felt when deliberating on it. Most of the questions I asked centered on how each individual viewed death, what they thought happens when a person dies, how they prepared for the event, and how their setting influenced their perspectives. As mentioned previously, the first questions were of age and the duration of time individuals had been in the retirement-nursing home. All elderly interviewed ranged in age from 72 to 83. The residents had been in the retirement-nursing home from just a few months to some years and thus supplied a wide range of experiences. In the next series of questions, I inquired as to how they were accepting and dealing with aging. Here are some responses from residents in the retirement-nursing home community:

“I try not to think about it. Take every day as it comes.”

“Terrible! Well, not terrible but it is very hard. Well, mostly physically. Lots of complications and I don’t like to be in pain. Otherwise I am the same as I always was.”

“Personally, hate it physically. Don’t mind it all mentally. I would not want to go through all that crap again. But the physical part, oh shit. I have gotten smarter and more patient. Also more compassionate towards others.”

“Not well, I do not like getting older at all. My body is so slow, and I have lots of aches. Sometimes my body does not even work right. The other day I had a hard time getting up because my knee would not straighten out. Well, I suppose that I am also a little slower speaker. I can tell sometimes that the staff [at the home] gets frustrated.”

Finding 3: elderly residing in personal residences coped better with aging and death

Most of the responses were negative in regards to the physical. Here is a response from an elderly individual living in his own home for comparison to the question of how they are accepting and dealing with aging:

“It’s difficult. It can get depressing at times, especially when you realize that it won’t really get better. It’s not a sickness, like the flu, that you eventually get over. But this is better than the alternative [death]. I get

mentally worn out as well. At times it seems like everything has gotten a little slower. But in a lot of ways I am smarter.”

Overall, it appeared that those living in the retirement-nursing home abhorred the aspect of aging physically yet enjoyed the wisdom they have gained throughout life. The elderly individuals who resided in their own homes seemed to cope better with aging, or at least have a better outlook towards it.

Finding 4: many elderly chose not to contemplate end of life

Subsequent to the initial background questions and those related to perspectives on aging, I inquired if in the retirement-nursing home setting they were faced with more death. Nearly all residents interviewed exhibited some sorrow as agreeing that there were more deaths in this environment. Here are some responses to the question from the residents:

“Yes, everyone is dying here, everyday someone dies. Well that is because all old people are here and that is what happens.”

“Oh, I think about a lot, and I think others do as well. But some have dementia, and I am not sure what they then think about it. We are all faced with people dying all the time here. It gets really sad.”

“Oh my, yes. It seems that every week there is a notice of someone passing on. It is really very sad.”

After establishing that there was, indeed, a prevalent number of deaths occurring in the retirement-nursing home environment, I began to ask more personal and probing questions about death. I inquired as to how often they think of dying and how often they contemplate the manner of dying. The responses were widely varied and quite different from the conformity of the previous question’s response. Here are some of the most interesting and contrasting responses from the residents:

“I try not to. In my sleep.”

“I try not to think about it. When you get old it just happens. In my sleep would be the best. I hope I don’t fall and hurt my self. That is why I am here now, because I fell.”

“Not too much, only just sometimes. But we prepare; we have our plots and tombstones that we want to have. I have a brother-in-law that is afraid to talk about death.[...] because of the stroke, I don’t want to go that way. We hope to go peacefully in our sleep.”

“A lot, as people go and learning that dementia is genetic, I think about it for me and my children and my grandchildren. When it happens, then I cannot help but think about it. [...] Of course I want to go peacefully and pain free. I hope to be able to say goodbye to all of my loved ones.”

“I try not to – ever. I would want to pass away in my sleep and never know that it happened.”

The elderly living in their own homes had similar and just as varied responses:

“I try not to think about it. At home, in my sleep, peacefully. I don’t want to be sick.”

“All the time. My own mortality gets put in perspective every day when I realize how fast things happen, how old I feel. [I would prefer to go] Peacefully, of course.”

There was a clear division between those who contemplated their own death and those who attempted to avoid thinking of death at all. More appeared to avoid thinking about death all together, yet all responded “peacefully in their sleep” when asked about the manner in which they would like die. I was not caught unsurprised by these responses, as I cannot image any other way in which the majority of people would choose to deacease. Contrary to the replies that showed many to avoid thinking of death were the few responses indicating that some had thought of and decided on the manner in which they would prefer to pass away. The response to die peacefully in sleep unanimously by all those asked reflects two of the great fears related to death – to suffer or to be in pain and to be conscious of the cessation of one’s own life. It was these fears that led to an increase in anxiety over death. The residents’ responses showed clear avoidance and wishes to go in peace by dying in their sleep. Only one resident responded that she hoped she would be able to “[s]ay goodbye to all of my loved ones.” I also asked a nurse about her perspective on how she thought the residents thought of death and the manner they would prefer to pass:

“The mentally sharp ones probably contemplate dying daily. There are a few that have stated they’re surprise and disappointment to wake to another day. [They would prefer to go] “Quietly, in their sleep without pain.”

She reinforced that the elderly all seemed to wish to die peacefully in their sleep. I would be interested to know if further investigation would reveal that the majority of people would, in fact, prefer to die in their sleep. I know it would certainly be my preference, but there may be some, perhaps those favoring notions of honor earned through valiance, who would prefer to expire in other ways.

Finding 5: religion and spirituality appeared to lessen degrees of death anxiety felt

Next, I questioned all interviewees about their spirituality or religious affiliations and if these affected their perspectives regarding death. I also inquired as to what supports spirituality offered when contemplating death. These questions were the ones which respondents most enthusiastically

answered. I was fortunate that those I interviewed were of a wide range of religious affiliations. Most were variations of Christianity and included Baptist, Episcopalian, Catholic, Lutheran, and Jehovah Witness. There was also an atheist. The responses were all quite varied but offered great insight into the comfort that people sought in religion when contemplating death. The responses all signified that religion or spirituality acted as a detractor from the levels of death anxiety felt. This is important to study and mention because, just as it is important to identify what factors contribute to death anxiety, it is imperative to know what may potentially reduce death anxiety felt by individuals. There was a recurring theme in the responses that death was not final and that something else, possibly life in heaven, happens after one dies. For reasons stated earlier, I can understand how this would be comforting to those who fear the finality of death and the cessation of life. On an interesting tangent, I interjected at this point in the interview an unplanned question as to who residents trust more – their priest or their doctor? While most of the respondents seemed very devoted in their religious views and esteemed their religions' exegesis, all responded that they trusted their doctor more. I found this fascinating because, at their advanced stage in life, medical science has yet been able to provide them with any solution to imminent death. I would suggest this be the subject of another ethnographic study.

Finding 6: individuals in poor health feared death more than those in good or moderate health

In an attempt to gain some quantitative data, I questioned all interviewed to rank in order of importance the following: pain and symptom management, prolongation of life, avoidance of prolongation of life, degree of control and informed consent, relieving burdens, relationships with loved ones, spiritual contentment, and financial security. Of the elderly residents within the retirement-nursing home community and the elderly living in their own homes, pain and symptom management received the most marks as being very important. Following that, relationships with loved ones was ranked second in importance, followed by degree of control and informed choice. Avoidance of prolongation of life and relieving burdens were each only mentioned twice by some interviewed. Even when the nurse was interviewed, she stated pain and symptom management were most important. These responses reflect two of the basic fears associated with dying and identify those factors that most contribute to death anxiety: fear of losing loved ones and fear of pain and suffering. Because there is actual suffering occurring for many, it would make sense that treatment of pain was of high importance.

At the concluding stage of interviews, I questioned if the individuals felt there was a correlation between their health and the level of anxiety felt about dying. All responses from the elderly residents, the elderly living in their own homes, and staff asserted that there was a connection between health and fears of dying. Here are their responses confirming that health influences the level of death anxiety one experiences:

“Of course, when someone does not feel good, especially at my age, they worry.”

“Definitely. Getting older means dying and no one looks forward to that.”

“Most definitely. You can see it in the sicker ones. They have the look of death and it has them scared.”

“Yes. Like I said before, it’s my own health and the way I feel that constantly put my mortality in perspective. Constantly reminding me that I am wearing out. But the aches and pains also do a good job to remind me that I am alive.”

“Yes. Younger individuals with Hodgkin or terminal cancer feel that they haven’t been here long enough with family and friends and don’t want to die.”

Findings 7 and 8: environment influenced degrees of death anxiety experienced; those living in the retirement-nursing home expressed aversion to being there

I then inquired if they felt there was a correlation between the living environment and the level of anxiety felt about dying. Again, all respondents, both the elderly residents in the retirement-nursing home and the elderly living in their own homes, agreed that there was a connection to their environment and the level of death anxiety one experiences. Almost all stated they did not want to be in the retirement-nursing home and would much prefer to be in their own homes. Again, here are their responses showing that environment influences the level of death anxiety felt:

“Yes, I want to go home. I don’t want to be here.”

“Well, yes. I do not want to be here. I would much prefer to go home or to my sons.”

“Not me personally, but I am sure that for others it does. Not many people want to be here. They would much prefer to be in their own homes.”

“Mh-huh. This place is all old people like me. Some even older. This is where people go to die.”

“Yes. I’ve used to work in a nursing home and I think that once you get to that stage in your life, you realize that you won’t be leaving, they kind of give up, wait to die sort of thing”

“For the majority of people it adds to their anxiety. Some people feel better about always having somebody there for them but most people see it as a beginning to the end. People hated to have their freedom and independence taken away. From what I saw I know I never want to go to a nursing home.”

These responses show an aversion to living in a retirement-nursing home and that being in such a facility contributes to one's death anxiety. As one resident stated, "[t]his is where people go to die." It is as if this individual thought himself or herself to have, upon relocating to the retirement-nursing home, welcomed in death and shunned out society of the living. Perhaps the environment of the retirement-nursing home negatively affected feelings of self-worth, hence adding further to degrees of death anxiety felt.

CONCLUSION AND SUGGESTIONS FOR FUTURE RESEARCH

In age-dense environments such as retirement-nursing homes, there exists an accumulation of variables contributing to feelings of death anxiety greater than that experienced by elderly individuals living in personal residences. These include not only individuals' advanced age but their experiences of being surrounded by peers vulnerable to fatal health conditions as well as their experiences of losing control over personal choice due to frequent intervention by facility staff. Additional variables, be they cultural, psychosocial, spiritual, economic, and/or environmental, may also exist. Without the time and access needed to determine what these might be, I left the field asking the following: to what extent does the appearance and "feel" of a setting influence feelings of death anxiety; how does one's constant proximity to medical staff, namely doctors and nurses, affect levels of apprehension felt; and, most importantly, how can medical personnel better equip themselves to relieve retirement-nursing home residents' fears and concerns? As I found in conducting research for this project, religion and spirituality offered to many informants a lessening of death-related fears. Perhaps there exist other tools capable of aiding as well, a variety of management skills to be developed. It is the recommendation of this researcher that the task of identifying these tools and developing these management skills be taken up now, if not for our aging selves then for our loved ones who presently live in retirement-nursing homes. Should we not do all that we can to relieve their burdens?

It might be that the best way to alleviate feelings of death anxiety among the elderly is by changing our culture from death-denying to death-accepting. Kubler-Ross (1973) supports this sentiment, arguing that problems associated with death-denying culture in the United States might be alleviated following exploration of other cultures' general acceptance of death. The more we come to accept death and view it as part of life's natural process, she argues, the less we are likely to fear it. To quote from Alбом's *Tuesdays with Morrie: An Old Man, a Young Man, and Life's Greatest Lesson*, a passage while in conversation with his dying professor, Morrie Schwartz, "'Everyone knows they're going to die [...] but nobody believes it. If we did, we would do things differently.' So we kid ourselves about death, I said. 'Yes. But there's a better approach. To know you're going to die, and to be prepared for it at any time. That's better. That way you can actually be more involved in your life while you're living.' [...] 'The truth is [...] once you learn how to die, you learn how to live'" (Alбом 1997:81-82).

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APPENDIX A: QUESTIONIER GUIDE FOR ELDERLY COMMUNITIES RESIDENTS, NON-RESIDENTS, AND CARETAKERS

The questions listed were used as a guideline, and thus should be noted that not all questions were asked verbatim, or even at all, depending on the reactions and behaviour of the interviewee.

Questions for Residents of the retirement home community:

- What is your age?
- How long have you been a member of the retirement community?
- Do you have close friends in this retirement community?
- [How are you accepting and dealing with aging?](#)
 - Besides physically, how have you changed?
- [Does it appear that in this setting you are faced with more deaths?](#)
- How have you been affected by the loss of family and friends?
- Does this affect your own perspectives on death?
- What do you feel happens when a person dies?
- [How often do you think of dying?](#)
- [How often do you contemplate the manner of dying?](#)
 - [How would you prefer to pass on?](#)
 - What would be your wish to happen upon your death?
- [How does your spirituality affect your perspectives on death?](#)
 - [What is your religious affiliation?](#)
- How do you relate or what do you pull from your religion while thinking about the process of dying?
- Are you more spiritual now than when you were younger?
- Do you feel that your age and circumstances are a factor to this?
- [What supports does spirituality offer you?](#)
- [Who do you trust more – your doctor or your priest?](#)
- Do you have any financial concerns that are linked with dying; like the costs of medical care, funeral fees, or inheritance to family and loved ones?

- Do you have a support network to address any of your end-of-life decisions and concerns?
 - Do you feel this setting of the retirement home helps with end-of-life planning?
- Do you feel well cared for and your wishes respected?
 - What degree of control do you want?
 - What degree of control do you want your family to have?
- When faced with end-of-life choices are you concerned with your ability or right to decide?
- When addressing end-of-life are physical or emotional needs of greater importance?
- What principles or values influence your end-of-life decisions?
- Please rate in importance to you:
 - Pain and symptom management
 - Prolongation of life
 - Avoidance of prolongation of life
 - Degree of control and informed choice
 - Relieving burdens
 - Relationships with loved ones
 - Spiritual contentment
 - Financial security
- Do you feel there is a correlation to your health and the level of anxiety you feel about dying?
- Do you feel there is a correlation to your living setting and the level of anxiety you feel about dying?
- Do you feel any of these views/answers would be different if you were living in your own residence opposed to a retirement home?
- Is there anything you would like to add?

Questions for individuals outside of the retirement home community for comparison:

- What is your age?
- How long have you been living in your house?
- How are you accepting and dealing with aging?
 - Besides physically, how have you changed?
- Does it appear that in this setting you are faced with more deaths?
- How have you been affected by the loss of family and friends?
- Does this affect your own perspectives on death?
- What do you feel happens when a person dies?
- How often do you think of dying?
- How often do you contemplate the manner of dying?
 - How would you prefer to pass on?
 - What would be your wish to happen upon your death?
- How does your spirituality affect your perspectives on death?
 - What is your religious affiliation?

- How do you relate or what do you pull from your religion while thinking about the process of dying?
- Are you more spiritual now than when you were younger?
- Do you feel that your age and circumstances are a factor to this?
- What supports does spirituality offer you?
- Who do you trust more – your doctor or your priest?
- Do you have any financial concerns that are linked with dying; like the costs of medical care, funeral fees, or inheritance to family and loved ones?
- Do you have a support network to address any of your end-of-life decisions and concerns?
 - What degree of control do you want?
 - What degree of control do you want your family to have?
- When faced with end-of-life choices are you concerned with your ability or right to decide?
- When addressing end-of-life are physical or emotional needs of greater importance?
- What principles or values influence your end-of-life decisions?
- Please rate in importance to you:
 - Pain and symptom management
 - Prolongation of life
 - Avoidance of prolongation of life
 - Degree of control and informed choice
 - Relieving burdens
 - Relationships with loved ones
 - Spiritual contentment
 - Financial security
- Do you feel there is a correlation to your health and the level of anxiety you feel about dying?
- Do you feel there is a correlation to your living setting and the level of anxiety you feel about dying?
- Do you know any one close that is living or had lived in a retirement home?
 - Were you able to gather any insights on their perspectives of death?
 - Do you feel living in a retirement home would add to the level of death anxiety a person experiences?
- Is there anything you would like to add?

Questions for nurses and caretakers of residents in the retirement home community:

- What is your age?
- How long have you been an employee/caretaker in the retirement community?
- Do you have close friends in this retirement community?
- How are you accepting and dealing with aging?
 - Besides physically, how have you changed?
- How do you perceive the residents accept and deal with aging?

- Besides physically, how do you perceive they have changed?
- Does it appear that in this setting you are faced with more deaths?
- How have you been affected by the loss of family and friends?
- Does this affect your own perspectives on death?
- What do you feel happens when a person dies?
- How often do you think of dying?
- How often do you contemplate the manner of dying?
 - How would you prefer to pass on?
 - What would be your wish to happen upon your death?
- How often do you think residents contemplate dying?
- How often do you think residents contemplate the manner of dying?
 - In your observations, how would most residents prefer to pass on?
- How does your spirituality affect your perspectives on death?
- Do you think spirituality affects resident's perspectives on death?
- What is your religious affiliation?
- How do you relate or what do you pull from your religion while thinking about the process of dying?
- What supports does spirituality offer when facing death?
- Who do you trust more – your doctor or your priest?
- Do you have any financial concerns that are linked with dying; like the costs of medical care, funeral fees, or inheritance to family and loved ones?
- Are there support networks available in the retirement home to address any end-of-life decisions and concerns?
 - Do you feel the setting of the retirement home helps with end-of-life planning?
- When faced with end-of-life choices are you concerned with your ability or right to decide?
 - What degree of control do you want?
 - What degree of control do you want your family to have?
- When faced with end-of-life choices are residents concerned with your ability or right to decide?
- When addressing end-of-life are physical or emotional needs of greater importance?
- When addressing end-of-life are physical or emotional needs of greater importance to the residents?
- What principles or values influence your end-of-life decisions?
- Please rate in importance to you:
 - Pain and symptom management
 - Prolongation of life
 - Avoidance of prolongation of life
 - Degree of control and informed choice
 - Relieving burdens
 - Relationships with loved ones
 - Spiritual contentment
 - Financial security

- How do you think residents would rate in importance:
 - Pain and symptom management
 - Prolongation of life
 - Avoidance of prolongation of life
 - Degree of control and informed choice
 - Relieving burdens
 - Relationships with loved ones
 - Spiritual contentment
- Do you feel there is a correlation between health and the level of anxiety one feels about dying?
- Do you feel there is a correlation between living setting and the level of anxiety one feels about dying?
- Is there anything you would like to add?