

A MIXED-METHODS EXPLORATION OF DEATH EXPOSURE
IN CERTIFIED NURSING ASSISTANTS: MODERATING
FACTORS AND IMPLICATIONS

by

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ABSTRACT

Certified Nursing Assistants (CNAs) are responsible for 80-90% of direct-to-resident care in skilled nursing home facilities (SNFs), and often develop close, family-like relationships with their residents. With SNFs becoming an increasingly common place of death for older adults, CNAs now find themselves engaging in end-of-life caregiving without proper training, or institutional support for the emotional outcomes. Moreover, little is known about the impact of frequent death exposure on CNAs. The present project examined these issues in a set of three interrelated studies, employing mixed-methods analyses. The first study found support for a new measure of attitudes toward advance care planning (ACP) in two samples, while finding that personal exposure to death is significantly related to more developed ACP attitudes. The second, qualitative study revealed CNAs' varying attitudes toward death, the importance of their relationships with residents, and the ways in which exposure to the dying process has influenced their ACP attitudes. Finally, while study 3 failed to find support for behavioral inhibition and experiential avoidance as moderators of the impact of death exposure on negative death attitudes, results supported the relationship between these variables and their impact on compassion fatigue. Moreover, positive death attitudes, and death exposure, were found to be more influential to ACP attitudes than negative death attitudes. Implications highlight researcher's imperative to develop interventions focusing on education and support of CNAs in their role as end-of-life caregivers to decrease high job turnover, and increase quality-of-care outcomes for residents.

DEDICATION

This project is respectfully dedicated to many woman and men who graced me with the opportunity to learn from their lived experience as CNAs. If I have done anything in these pages, I hope above all to have been true to your stories, and to provide in a small way acknowledgment of your work: both mundane and meaningful, ambivalent and life-changing.

LIST OF ABBREVIATIONS AND SYMBOLS

<i>M</i>	Mean: the sum of a set of measurements divided by the number of measurements in the set
<i>N</i>	Total number in a sample
<i>P</i>	Probability associated with the occurrence under the null hypothesis of a value as extreme as or more extreme than the observed value
<i>r</i>	Pearson product-moment correlation
<i>df</i>	Degrees of freedom: number of values free to vary after certain restrictions have been placed on the data
<i>F</i>	Fisher's F ratio: A ratio of two variances
<i>SD</i>	Standard deviation
α	Cronbach's alpha: a coefficient of internal consistency
<i>t</i>	Computed value of <i>t</i> test
β	Beta; Standardized coefficient
<	Less than
>	Greater than
=	Equal to

ACKNOWLEDGMENTS

As someone who has felt on many occasions the anxiety of the blank page, with all of its possibilities and potential failures, I could never have imagined some years ago the affection I have felt for this project and the people who made it possible.

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“O death, where is your victory?”

O death, where is your sting?”

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INTRODUCTION

In the United States and other Western nations, nursing homes are rapidly becoming a leading place of death for older adults (Gomes & Higgenson, 2008; Gruneir et al., 2007; Wilson et al., 2009). In 2014, some 25.4% of adults over 65 years of age died in a nursing home (CDC National Center for Health Statistics, 2015). This percentage is even higher for non-Hispanic white older adults, at 29.3% (CDC National Center for Health Statistics, 2015) and for individuals with dementia, at 66.9% (Mitchell, Teno, Miller, & Mor, 2005). Considering that nearly 40% of nursing home residents are hospitalized during their final 30 days of life, the number of individuals receiving some end-of-life care in nursing homes may be even higher than the estimates reflecting the individuals who die there (Miller, Gonzalo, & Mor, 2001; Oliver, Porock, & Zweig, 2005).

Nursing home staff members, primarily certified nursing assistants (CNAs), are on the front lines of patient care in long-term-care settings. CNAs provide the majority of daily care to residents and have more patient contact than any other staff members (Institute of Medicine, 2004; Dawson & Surpin, 2001). Perhaps owing to this high exposure, a lack of training, or both, CNAs report higher levels of death anxiety and negative attitudes toward caring for the dying than do other nursing staff (i.e., licensed practical nurses and registered nurses; Demmer, 2000).

Previous literature has highlighted ways in which the experiences, beliefs, attitudes, and knowledge of care providers related to end-of-life issues affect critical outcomes (e.g., Peter et al., 2013a; Peter et al., 2013b). Death avoidance, for example, has been linked to negative views on caring for the dying among nurses (Braun, Gordon, & Uziely, 2010). Similarly, nurses who

reported more death anxiety were less comfortable when engaging in end-of-life related communications with patients (Deffner & Bell, 2005). Despite the consistent finding that knowledge and attitudes held by care staff impact the quality of life for residents at the end of life, CNAs still lack proper palliative training (Forbes-Thompson & Gessert, 2005; Hospice and Palliative Nurses Association, 2005; Wholihan & Anderson, 2013).

Furthermore, results on the impact of exposure to death remain highly mixed with few satisfactory hypotheses explaining the discrepant nature of findings (e.g., Aradilla-Herrero, Tomas-Sabado, & Gomez-Benito, 2013; Chen, Del Ben, Fortson, & Lewis, 2006; Grant & Wade-Benzoni, 2009; Schell & Zingler, 1984; Thorson & Powell, 1996; Yeaworth, Kapp, & Winget, 1974). Two concepts appear promising as potential moderators between exposure to death and various outcomes (e.g., death attitudes, attitudes toward future care planning), thus helping to make sense of the mixed literature: experiential avoidance and behavioral inhibition. At the time of the current study, these concepts were unexamined related to the concepts of death exposure and death-related attitudes in general, and as well as specifically related to CNAs.

The present studies add to the literature by examining how contributing factors (e.g., occupational death exposure, personal death exposure, demographic characteristics) relate to death attitudes (e.g., fear, avoidance, acceptance) and how those death attitudes subsequently relate to attitudinal (e.g., willingness to engage in preparation for future care) and psychological/emotional outcomes (e.g., compassion fatigue) in a population of CNAs working in the Southern United States. Moreover, the present research is especially unique in its examination of novel potential moderators to explain previously contradictory findings. After reviewing the broad role of the nursing home context and CNAs at the end of life, each of the three studies comprising the current project is discussed. The first study describes the results of

the measurement development of the My Aging Preparation Scale (MAPS) and its data in two different population samples. The second study presents the qualitative findings of focus groups of CNAs from Tuscaloosa and Birmingham nursing homes discussing their experiences caring for dying residents. Finally, the third study presents the main quantitative findings, including the proposed moderation models relating death exposure to death attitudes.

The Nursing Home Context for Dying

With the knowledge that many individuals die in nursing homes, it is important to understand how the process unfolds in these settings. In 2011, some 28,000 individuals were in nursing homes in the state of Alabama (National Center for Health Statistics, 2013). Nationally, there are more than 16,000 nursing home facilities capable of housing 1.7 million individuals (Jones, Dwyer, Bercovitz, & Strahan, 2009). Despite the increasing frequency of death in nursing homes, the policies of the long term care settings have not evolved to deal with these changes. Studies have documented that use of end-of-life care (i.e., palliative and hospice services) in nursing homes is low (Bercovitz, Decker, Jones, & Remsburg, 2008, Miller, Lima, Looze, & Mitchell, 2012; National Hospice and Palliative Care Organization, 2012). More broadly, common end-of-life issues such as pain and discomfort are often poorly managed (Bostick, Rantz, Flesner, & Riggs, 2006; Brandt et al., 2005). Key aspects of the culture of nursing homes as restorative facilities are diametrically opposed to the needs of those near death, creating a variety of difficulties for staff and unmet needs for dying patients (Keay, 1999; Lopez, Amella, Strumpf, Teno, & Mitchell, 2010; Mukamel et al., 2012; Zheng, Mukamel, Caprio, & Temkin-Greener, 2012). In fact, in the United States, legislation (i.e., Omnibus Budget Reconciliation Act of 1987) has been passed requiring facilities to “achieve the highest practicable level of functioning” for their residents, and many states have similar laws that create a professed

restoration framework for nursing home care, while pushing the constant reality of death to hidden corners (see Kelly, 1989 for an analysis).

Though certainly an important goal, the mandate that nursing homes be primarily places of restoration poses a problem for those who care for the 25% of individuals who will die in one of these facilities. Foremost among these issues is a lack of guidance and training for identifying a clear prognosis of death, which both inhibits proper palliative treatment as well as complicates other care activities for residents and staff alike (Forbes, Bern-Klug, & Gessert, 2000; Porock et al., 2005; Thompson & Oliver, 2008; Waldrop & Nyquist, 2011). CNAs commonly report that inadequate training is a major barrier to providing better care to residents (Ersek, Kraybill, & Hansberry, 2000; Roscoe & Hyer, 2008) and national recommendations have been made emphasizing the importance of addressing knowledge gaps (Hospice and Palliative Nurses Association, 2002; Hospice and Palliative Nurses Association, 2005). When training programs are implemented, CNA participants respond positively and increase in their knowledge about palliative care issues (Wholihan & Anderson, 2013).

Another unintended consequence of the prominent restoration culture is the relegation of death and dying in nursing homes to a secret space, “backstage,” where even staff members are conflicted between the two messages of restoration and death (see Froggatt, Hockley, Parker & Brazil, 2011; Oliver, Porock, & Oliver, 2006; Oliver et al., 2005). Providing adequate training and support programs would not only improve identification of those in a palliative population, but bring the topic of death in nursing homes to a public, open space among staff thereby decreasing ambivalence and confusion.

Following predictably from the mismatch between legislation and reality, research has highlighted the ways in which end-of-life experiences in nursing home settings leave much to be

desired. For example, families of older adults who died in a nursing home reported that nursing home residents were less likely to be treated with respect at the end of life, compared to those who died in a hospital or with home hospice (Teno et al., 2004). Staff, including both physicians and CNAs, is perceived to be stretched too thinly to properly care for residents at the end of life (McGilton & Boscart, 2007; Shield, Wetle, Teno, Miller, & Welch, 2005). For staff, too, research indicates outcomes such as negative effects on work and home life resultant from caring for individuals near the end of life (Wilson & Kirshbaum, 2011). For example, a survey of long-term care staff revealed that 54% reported feeling sad, 26% reported crying, and 25% reported feeling unable to accept a death within the past month of work (Rickerson et al., 2005).

Certified Nursing Assistants

CNAs are in charge of helping residents perform a range of intimate and physically demanding tasks such as bathing, toileting, eating, dressing and grooming. Though they only comprise 65% of the nursing staff in facilities, CNAs provide 80-90% of direct care to nursing home residents, assisting primarily with activities of daily living (Dawson & Surpin, 2001; Institute of Medicine, 2004). Despite the fact that these activities are crucial to the health and well-being of residents, CNAs are often considered to be bottom-rung, unskilled labor in nursing homes. As one CNA poignantly told researchers, “[Nursing home administrators] think we are nothing but butt wipers... that’s all” (Dodson & Zinavage, 2007). Wages reflect this widespread undervaluation. Starting pay for CNAs is approximately \$8.72 per hour (Donoghue, 2010). Compared to RNs and LPNs, who make upwards of \$16-18 per hour, CNAs perform nearly 3.5 to 5 times the amount of work (hours per patient; Donoghue, 2010). Job satisfaction is often moderate or low, with frequently reported concerns including inadequate staffing, high workload, and frequent resident deaths (Cherry, Ashcraft, & Owen, 2007; Zakoscielna &

Parmelee, in preparation). Jenull & Brunner (2008), for example, demonstrate through a mixed-method study that nursing home staff views the death of residents as a main stressor of their job. It is not surprising that CNAs have an extraordinarily high rate of job turnover: 75% each year (Donoghue, 2010). Furthermore, high turnover rates impede efforts to properly train staff regarding end-of-life issues both formally and through employee-to-employee mentorship (Hayes et al., 2012; Rice, Coleman, Fish, Levy, & Kutner, 2004).

Ironically, against this backdrop of difficult working conditions and poor compensation, another narrative is being told. As part of the culture of nursing homes, administrators and staff have adopted a norm of fictive kinship with residents (see Dodson & Zincavage, 2007 for an excellent analysis). CNAs are told to care for residents as if they were their own mothers or grandparents (Hanson, Henderson, & Menon, 2002; Lopez, 2007). Though little research has been done on the impact of this informal but pervasive aspect of resident-staff relations, it is reasonable to suspect that this imperative magnifies the emotional toll that resident deaths exact on CNAs. For example, one study of CNAs participating in a support group suggests that many report experiencing grief associated with caring for dying residents (Burack & Chichin, 2001).

Despite the potential attractiveness of a fictive family of residents and staff printed on brochures, this culture is inevitably problematic. First, embedded in this fictive kin relationship is a propensity to exploit the CNAs to work more than their compensation would suggest. In fact, CNAs are the most likely of all nursing home staff to work overtime hours (Donoghue, 2010). Although some of the overtime work may be a result of economic hardship, CNAs also express concern for residents that extends past their paid hours, with many admitting to coming in on days off or worrying about residents after their shifts (Dodson & Zincavage, 2007). In addition, particularly salient to bereavement topics, the fictive kinship culture implies that CNAs become

very close to residents and invest emotionally in their relationships with them (Moss, Moss, Rubinstein, & Black, 2003). Interestingly, however, though the “family model” is quite pervasive throughout nursing home culture, the same model that once encouraged intimacy in care breaks down during and following the death of a resident. CNAs are often discouraged from mourning their residents as if they were family, disallowed from attending funerals, and sometimes not told when the resident has passed away (Dodson & Zinbarg, 2007). In fact, allowing nursing home staff to have time off to attend funeral services emerges as a common suggestion to improve the care of dying residents (i.e., Hanson et al., 2002).

Impact of suffering on CNAs. Whether or not it is supported by the structure and culture of the nursing home system, CNAs undoubtedly work in a blurred space between paid caregiver and more intimate family member. Work on the impact of stress and suffering on caregivers informs the current discussion by acknowledging this ambiguous relationship and the potential for negative outcomes that may result. Considering the stressors specific to the nonprofessional, or nonpaid, caregiver role, Monin and Schulz (2009) developed the Caregiver Stress-Health Model (Figure 1). The Monin and Schulz (2009) Caregiver Stress-Health Model not only recognizes the strain that results from the support-related demands of caregiving, but also highlights the connection between a care recipient’s suffering (as displayed through various outward signs and symptoms) and a caregiver’s emotional distress. Evidence suggests that CNAs likely witness a great deal of physical and emotional suffering of residents near death (Allen, Burgio, Fisher, Hardin, & Shuster, 2005; Allen et al., 2003; Fisher et al., 2002; Robinson, 2010). Moreover, distress such as pain intensity and greater physical limitations have been linked to higher burden in CNAs (Norton, Allen, Snow, Hardin, & Burgio, 2010).

The Monin & Schulz model offers a pathway explaining how both physical disability and suffering behaviors displayed by an older adult contribute to caregiver stressors, thus affecting caregiver outcomes such as psychological distress and avoidance. The Caregiver Stress-Health

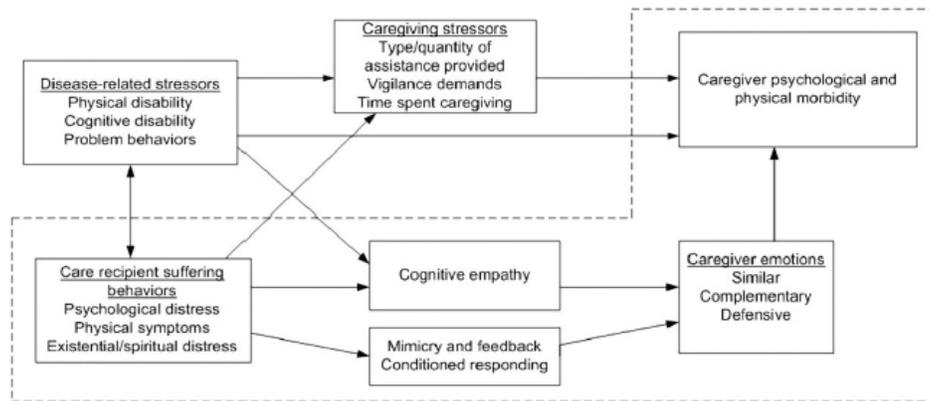


Figure 1. Monin & Schulz (2009) Caregiver Stress-Health Model

Model offers two possible response patterns caregivers may exhibit in response to a care recipients' suffering: cognitive empathy and conditioned emotional response (Monin & Schulz, 2009). Cognitive empathy refers to the shared or complementary (e.g., love or concern in response to distress) emotional experience of the caregiver to the care recipient in response to his or her suffering (Monin & Schulz, 2009). Conditioned emotional responses occur when the caregiver has paired certain emotions with past experiences of care recipient suffering (e.g., becoming angry when their patient is in pain due to a history of difficulty dealing with their pain) and can cause a caregiver to display defensive emotions (Monin & Schulz, 2009).

Indeed, previous research has examined the perception of physical suffering by CNAs (Herman, Johnson, Richie, & Parmelee, 2009; Reynolds, Henderson, Schulman, & Hanson, 2002; Zakoscielna & Parmelee, 2013). Overall, evidence suggests that nursing home staff likely underestimate the pain of their residents; however, CNAs appear to be more accurate than LPNs (Engle, Graney, & Chan, 2001; Kutner, Bryant, Beaty, & Fairclough, 2006).

Risk and protective factors. Finally, it is important to consider the risk and protective factors which may influence outcomes such as grief reactions and/or caregiver role strain for CNAs. Neimeyer and Burke (2012) outlined three main categories of factors—background, death-related, and treatment-related—which uniquely contribute to risk in bereavement. Regarding background, two factors may lead to increased risk of bereavement complications: ethnic minority status and close kinship to the dying patient. Research indicates that African Americans are more likely to experience complicated bereavement symptoms than are Caucasians (Goldsmith, Morrison, Vanderwerker, & Prigerson, 2008; Laurie & Neimeyer, 2008; Neimeyer, Baldwin, & Gillies, 2006). This is important, considering that nationally 46.6% of CNAs are nonwhite, with likely even higher percentages of African American staff in the Southern United States (Jones et al., 2009; U.S. Census Bureau, 2012). Regarding relationship to the dying patients, CNAs overwhelmingly report caring about the well-being of their patients. For example, over 90% of CNAs report that they took their current CNA job because they wanted to help people and the majority report that this is the reason they have not left, despite concerns about wages and hours (Jones et al., 2009). As previously mentioned, CNAs provide the vast majority of care for residents (Dawson & Surpin, 2001; Institute of Medicine, 2004), spend more time with residents than any other staff members (Donoghue, 2010), and are entrenched in fictive kinship relationships with their patients (Dodson & Zincavage, 2007). These factors may all contribute to an intimate relationship at risk for bereavement.

The next set of risk factors, those related to the death event itself, includes bereavement overload and dissatisfaction with death notification. Anticipating loss and dealing with death in residents often provokes a grief response in long term care staff (Holman, 2008). Rickerson and colleagues (2005) reported that staff most likely to experience high numbers of grief symptoms

included those who have more experience with death in the past month, a likely occurrence for full time staff. Moreover, in line with the pervasive disrespect and devaluation of their position, CNAs are too often not adequately informed of the death of residents under their care (Dodson & Zinzavage, 2007; Cherry et al., 2007).

A final risk factor, categorized by Neimeyer as “treatment related,” is caregiver burden. Indeed, having examined the model presented by Monin & Schulz (2009), it is clear to see how high rates of burden may lead to negative outcomes for caregivers, whether formal or informal. Research documents that these outcomes are relevant for CNAs, finding high rates of staff burnout, turnover, and job dissatisfaction (Banaszak-Holl & Hines, 1996; Castle & Enberg, 2006; Cherry, Ashcraft, & Owen, 2007; United States General Accounting Office, 2001).

CNAs also possess a set of insulating factors which may protect them from the negative outcomes of exposure to repeated loss at work. For example, research has highlighted the protective value of social support (Linley & Joseph, 2005) and positive staff interactions (Hanson et al., 2002). Furthermore, as would be predicted by Terror Management Theory (see below), research has largely supported the connection between religious and spiritual belief systems and more positive outcomes in the face of repeated bereavement events (Greenberg, Pyszczynski, & Solomon, 1986; Greenberg et al., 1990; Rosenblatt, Greenberg, Solomon, Pyszczynski, & Lyons, 1989). Among older adults, women, and minorities, religion is cited more frequently than any other form of coping against negative emotional experiences (Dunn & Horgas, 2004). Holland and Neimeyer (2005) studied various end-of-life care providers to demonstrate experimentally that reliance on daily religious activities decreases emotional burnout. Other researchers have used qualitative methods and found that religious involvement is

an oft-used strategy to avoid negative psychological outcomes (Glas, 2007; Harris, Allen, Dunn, & Parmelee, 2013; Pierce, 2007; Swetz, Harrington, Matsuyama, Shanafelt, & Lyckholm, 2009).

Conclusion

In conclusion, CNAs represent a division of end-of-life caregivers not frequently recognized in their role as such. A host of factors related to the structure of skilled nursing facilities, the position of CNAs, and the individuals who are employed as CNAs, make them a complex and important population to include in the research being done to better understand and improve end-of-life outcomes for older adults. As suggested by Monin and Schulz's work (2009), CNAs are likely to be emotionally impacted by witnessing the suffering of residents via their relationships, and the intensity of their caregiving roles. This process is likely compounded at the end of life, when interpersonal caregiving may intensify even more (e.g., due to increased pain and confusion) and become more relational. Thus, the role of the present research is to examine both quantitatively and qualitatively the ways in which CNAs are or are not influenced by such end-of-life caregiving, and to clarify ways occupational exposure to death influences specific related outcomes (i.e., attitudes toward advance care planning and job-related compassion fatigue).

STUDY 1: MY AGING PREPARATION SCALE (MAPS): VALIDATION OF A NEW SCALE MEASURING ATTITUDES TOWARD ADVANCE CARE PLANNING IN TWO SAMPLES

For decades, the vast majority of literature around end-of-life care planning has heralded a single theme: despite the many advantages to doing so, most individuals simply do not think about, plan for, and communicate preferences for their own future care (Houben, Spruit, Groenen, Wouters, & Janssen, 2014). For those who do, a host of positive outcomes are associated, including knowledge of and adherence to their wishes (Houben et al., 2014), lower stress and anxiety for family and loved ones (Detering, Hancock, Reade, & Silvester, 2010), earlier referral to beneficial hospice care (Wright et al., 2008), and lower healthcare costs during the last week of life (Zhang et al., 2009). However, execution of an advance directive alone is often not enough to ensure high quality end-of-life care (Ditto et al., 2001; Fagerlin, Ditto, Hawkins, Schneider, & Smucker, 2002; Kirschner, 2005). The current study aims to examine an emerging approach to enhancing patient and family outcomes related to future care planning, based on the transtheoretical model (TTM; Prochaska & Velicer, 1997). Specifically, we present and explore a new tool, developed via community-based participatory research feedback, for structuring and facilitating discussions about future care preferences, the My Aging Preparation Scale (MAPS). After a brief review of relevant literature, the tool's psychometric properties are examined in two samples: individuals working as certified nursing assistants (CNAs) in local nursing home facilities, and college students taking an introductory psychology course.

While execution of an advance directive, a legal document outlining specific wishes of an individual should they become incapacitated, has been a common approach to end-of-life care

planning, the usefulness of such documents has been questioned (Moorman & Inoue, 2013). For example, lack of awareness is a common barrier to completion of advance directives (Rao, Anderson, Lin, & Laux, 2014). Furthermore, for individuals considering advance care planning, the idea of predicting their wishes in a hypothetical future situation (i.e., affective forecasting) is sometimes uncomfortable and may be of limited value (Hawkins, Ditto, Danks, & Smucker, 2005). Advance directives, though changeable, can be seen as inflexible and thus may be perceived to be frightening. Indeed, research has long supported our shortcomings in affective forecasting (Gilbert, Pinel, Wilson, Blumberg, & Wheatley, 1998), including the lack of an individual's ability to predict how they might feel following a hypothetical medical event (Smith, Loewenstein, Jankovic, & Ubel, 2009).

Therefore, some researchers have suggested complementary ways to enhance advance care planning and improve outcomes. One such method is that of increasing communication regarding end-of-life care, specifically in continuous, process-based approaches (Davison & Simpson, 2006; Moorman & Inoue, 2013; Tulsky, 2005), and thus better preparing individuals to make decisions as needed (i.e., compared to making comprehensive decisions about unknown future healthcare situations; Sudore & Fried, 2010). As posited by the TTM, changes in behavior, such as those relevant to advance care planning, are the result of a progression through multiple psychological and behavioral phases beginning with pre-contemplation and moving through contemplation, preparation, action, and maintenance (Fried, Bullock, Iannone, & O'Leary, 2009; Prochaska & Velicer, 1997; see Figure 2). In this way, behaviors related to making formal plans for future care are more accurately viewed as the outcome of a multi-step process than as a binary on or off. Such a process is facilitated by conversations with trusted family members, as

well as healthcare providers, which examine current beliefs, preferences, and barriers to preparation for future care.

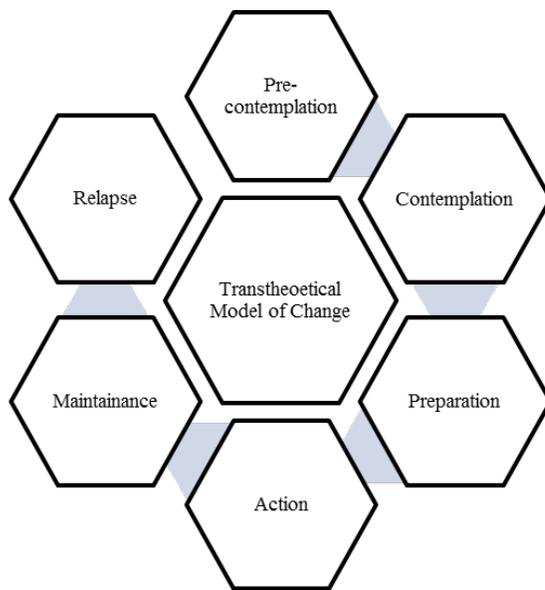


Figure 2. Prochaska & Velicer (1997) Transtheoretical Model of Change (TTM).

The Preparation for Future Care (PFC) Scale (Sorensen & Pinquart, 2001), was selected to serve as the basis of a tool that would help individuals assess their own future care planning attitudes. The original PFC contains five subscales which roughly align with the stages of the TTM. Specifically the PFC measures an individual's awareness of their future care needs (pre-contemplation, contemplation), avoidance of such awareness (pre-contemplation, contemplation), the extent to which they have sought out information to help them make decisions (preparation), if any preferences have been developed (action), and what concrete plans have been made (action). Despite its strengths as a theory-based measure with good reliability, the PFC proved to be problematic when used in a low SES, rural community sample (R21NR012250). Thus, the measure was adapted with the primary goal of simplifying language and concepts, and the secondary goal of increasing item specificity (e.g., eliminating multiple questions contained in a single item).

Measurement Adaptation

In order to ground the measurement development in a community-based participatory research (CBPR; Israel, Schulz, Parker, & Becker, 2001; Schulz et al., 2005; Viswanathan et al., 2004; Wallerstein & Duran, 2006) methodology, researchers contracted with a community advisory board (CARDS) working in collaboration with the Wisconsin Network for Research Support. Via a 90-min telephone consultation session, four members of the CARDS group (two research staff and two community advisors) reviewed the PFC items and response options. Described as “people who bring into the research process voices of racial, ethnic and socioeconomic groups who are rarely represented in research planning or activities,” the CARDS are individuals from the community who, once trained, partner with researchers to offer advice on materials such as measures, intervention approaches, pamphlets, and recruitment flyers. The group was originally supported by a National Institute of Health grant for community-based participatory research to the University of Wisconsin-Madison.

After consultation from the CARDS group, the new measure (My Aging Preparation Scale—MAPS) was viewed by the research team and a local Project Advisory Council (Project SOAR, PCORI Contract #1097) as more accessible to individuals with lower literacy levels. Notable changes included separation of single, double-barreled items into separate items that ask one question only, language simplification, and rewording of the response options (see Appendices A & B to compare the original PFC to the adapted MAPS). The resultant measure has 18 items in comparison with the original 15-item measure.

Present Study

The overarching goal of the present study was to examine the psychometric properties of the MAPS as a newly developed tool. Specifically, the present study sought to examine the

MAPS via confirmatory factor analysis to test the hypothesis that the measure would retain the original five-factor structure present in the parent-PFC measure (Sörensen & Pinquart, 2001). Following confirmatory factor analysis, the present study set out to examine a set of hypotheses which could serve as a first round of testing of the validity of the measure as a TTM-based tool.

Hypotheses for this portion of analyses included: 1) for both CNAs and college students, subscales representing more advanced levels of behavior change (i.e., developing preferences and concrete planning) would be less developed than subscales representing less advanced levels of behavior change (i.e., awareness, avoidance, and gathering information); 2) overall, the sample of CNAs would describe more highly developed attitudes across the five subscales (i.e., more awareness, less avoidance, more gathering information, more developed preferences, and more concrete planning) than would the college student sample; 3) for the college student sample, participants endorsing more death-exposure would endorse more developed preferences across the subscales than participants with less death-exposure.

Study 1 Data Analysis

To address the first goal of the project, a confirmatory factor analysis was conducted using MPlus Software (Muthén & Muthén, 2011). Baseline model specifications for both CFAs included uncorrelated latent factors and residuals, and the variance for the first indicator for each of the five factors was set to one. Given the impact of sample size on chi-square, three other fit statistics were pre-selected to determine model fit (Hooper, Coughlan, & Mullen, 2008): Root Mean Square Error of Approximation (RMSEA; acceptable fit $<.06$); Comparative Fit Index (CFI; acceptable fit $>.90$); and Tucker-Lewis Index (TLI; acceptable fit $>.90$). ANOVA and bivariate correlation analyses were conducted in SPSS Version 22.0 (IBM Corp, 2013).

Study 1 Methods

Participants and Procedure

Two independent participant samples were utilized in the current project. Both were IRB approved (see Appendices C & D).

College student sample. Data were collected from N=999 college students through the University of Alabama's Psychology Subject Pool Online System. They were recruited from the University of Alabama's Introductory to Psychology courses via an online centralized portal of all available experiments (i.e., participants were able to self-select into the present study) and they received 0.5 credits towards their course requirements for participation. Potential participants were given information about the study in the informed consent page before they agreed to participate. Participants were also given a basic definition of "advance care planning," so as to reduce effects from unfamiliarity with the term. After cleaning data for missing items, and careful responding, the sample size was N=772.

Certified Nursing Assistant sample. Data were collected in person from N=138 CNAs who are currently employed in one of five local (Tuscaloosa, Birmingham, and Moundville) skilled nursing home facilities. Twenty-eight participants came from the pilot phase of data collection, and 110 participants from the full study phase of data collection. In both cases, responses on the MAPS were collected as part of a larger study, and counter-balancing schemes were employed to reduce the impact of other measures on responses to the MAPS.

Prior to data collection, nursing home administrators from each of the facilities were contacted and asked to meet in order to obtain letters of support. During this meeting, the purpose and procedures of the study was explained and administrators had an opportunity to ask questions. After IRB approval, the study was advertised to potential participants via IRB-

approved flyers in areas visible to staff members (e.g., staff break rooms, nurse's station) and word-of-mouth. Some facilities made announcements to staff to inform them of the study; in these cases, research staff made an extra effort to be clear that the study was entirely voluntary and in no way required of them by their employer.

All interested parties received an informed consent document describing the procedures and minimal potential risks (e.g., possible discomfort over presented topics, fatigue). Participants who voluntarily agreed to be in the study completed the consent and accompanying packet of surveys. Participants were encouraged to enjoy snacks provided by the research staff during or after completion of the surveys. After completion of the packet, participants were given \$5 in the main study, and \$10 in the pilot study, and thanked for their time and efforts. Research assistants asked participants to sign a receipt acknowledging receipt of the cash payment, and were told their signed receipts were kept separate from their survey answers.

Study 1 Measures

Across both samples, basic demographics including age and race/ethnicity were collected.

Death exposure. College students were asked to denote whether or not they had previously had any experience working in a nursing home setting. Both college students and CNAs were asked to complete an open ended question assessing how many “close family and friends” they had lost over the course of their lifetimes.

My Aging Preparation Scale. My Aging Preparation Scale (MAPS; unpublished, 2013). The MAP Scale (Appendix B) was developed based on the Preparation for Future Care Needs (Sorensen & Pinquart, 2001). Based on theoretical understanding of advance care planning, the MAPS purports to measure the five latent constructs assessed in the original PFC (Awareness,

Avoidance, Gathering Information, Developing Preferences, and Concrete Planning factors), while being more accessible to respondents (Flesh-Kincaid Reading Level=3.6). The 18-question measure was developed through collaboration with a Wisconsin-based community advisory board and several rounds of collaborative revision based on feedback.

Study 1 Results

Demographics are presented in Table 1. Unsurprisingly, CNAs were significantly older than college students (Welch $t(137) = 19.59, p < .001$). As predicted, the CNA participants reported greater overall exposure to death in comparison with college students. On average, CNAs had worked 12.62 years (SD=9.13) in the position. Of the college student participants, only 11.1% had worked in some capacity in a nursing home. CNAs also reported significantly greater personal loss (Welch $t(149) = 11.19, p < .001$), having lost, on average, 9.34(SD=6.22) individuals with whom they had close relationships, compared with college students' 3.34(SD=2.39).

Table 1.

Demographics of College Student and CNA Samples

	Age Mean(SD)	Gender	Race/Ethnicity
College Students N=772	18.6(0.96)	Female: 73.4% Male: 26.3%	African American: 6.9% Caucasian: 91.3% Asian American: 1.8%
Certified Nursing Assistants N=138	38.26(11.78)	Female: 97.8% Male: 1.4%	African American: 93.5% Caucasian: 4.3% Other: 0.7%

Cronbach's alpha values for the MAPS in the current sample ranged from questionable to good, with most subscales generating acceptable alpha values. The Awareness subscale showed good reliability ($\alpha = .81$) in the CNA sample, and acceptable reliability ($\alpha = .74$) in the college student sample. Avoidance showed acceptable reliability in both groups (CNA $\alpha = .78$; student $\alpha =$

.74). The Gathering Information subscale showed good reliability in the CNA sample ($\alpha=.87$) and acceptable reliability in the college student sample ($\alpha=.79$). Developing Preferences was the subscale showing the weakest internal consistency, with questionable range alphas in both groups (CNA $\alpha=.65$; student $\alpha=.64$). Concrete Planning showed acceptable reliability in both groups (CNA $\alpha=.78$; student $\alpha=.71$). Overall, in both groups, the entire MAPS showed good reliability, with an alpha of .83 in the CNA sample, and .82 in the college student sample.

Confirmatory Factor Analysis

Confirmatory factor analysis (Tables 2 and 3) revealed that the pre-existing five-factor model (i.e., of Awareness, Avoidance, Gathering Information, Developing Preferences, and Concrete Planning) had close fit and was plausible across both samples. In the sample of college students, the model generated close fit: $\chi^2=233.03$, $df=108$, $p<.001$; $RMSEA=.039$ [.032-.046]; $CFI=.97$; $TLI=.96$. Likewise, for the CNA sample, results also indicated acceptable fit: $\chi^2=205.03$, $df=124$, $p<.001$; $RMSEA=.069$ [.052-.085]; $CFI=.93$; $TLI=.91$. Due to the impact of sample size, and the number of indicators, $RMSEA$ and CFI/TLI proved to be more reliable fit statistics. Models, with standardized parameter estimates, are presented in Figures 3 and 4.

Table 2.

Goodness of fit indices for MAPS 5-Factor Model in CNA Sample

	$\chi^2(df)$	$\Delta \chi^2(df)$	RMSEA [90% CI]	CFI	TLI
Model 1: 5 Factor Model	232.33(125)	--	.079 [.063-.095]	.91	.89
Model 2: 5-Factor Model, correlated residuals*	205.03(124)	27.3(1)	0.69 [.052-.085]	.93	.91

*Residual variance between MAPS1 and MAPS2 were correlated
 CI=Confidence Interval; RMSEA=Root Mean Square Error of Approximation;
 CFI=Comparative Fit Index; TLI=Tucker-Lewis Index

Table 3.

Goodness of fit indices for MAPS 5-Factor Model in College Student Sample

	$\chi^2(df)$	$\Delta \chi^2(df)$	RMSEA [90% CI]	CFI	TLI
Model 1: 5 Factor Model	506.22(125)	--	.063 [.057-.069]	.91	.89
Model 2: 5-Factor Model, correlated residuals*	297.10 (123)	209.12(2)	0.043 [.037-.049]	.96	.95

*Residual variance between MAPS1 and MAPS2, and MAPS14 and MAPS15 were correlated
CI=Confidence Interval; RMSEA=Root Mean Square Error of Approximation;
CFI=Comparative Fit Index; TLI=Tucker-Lewis Index

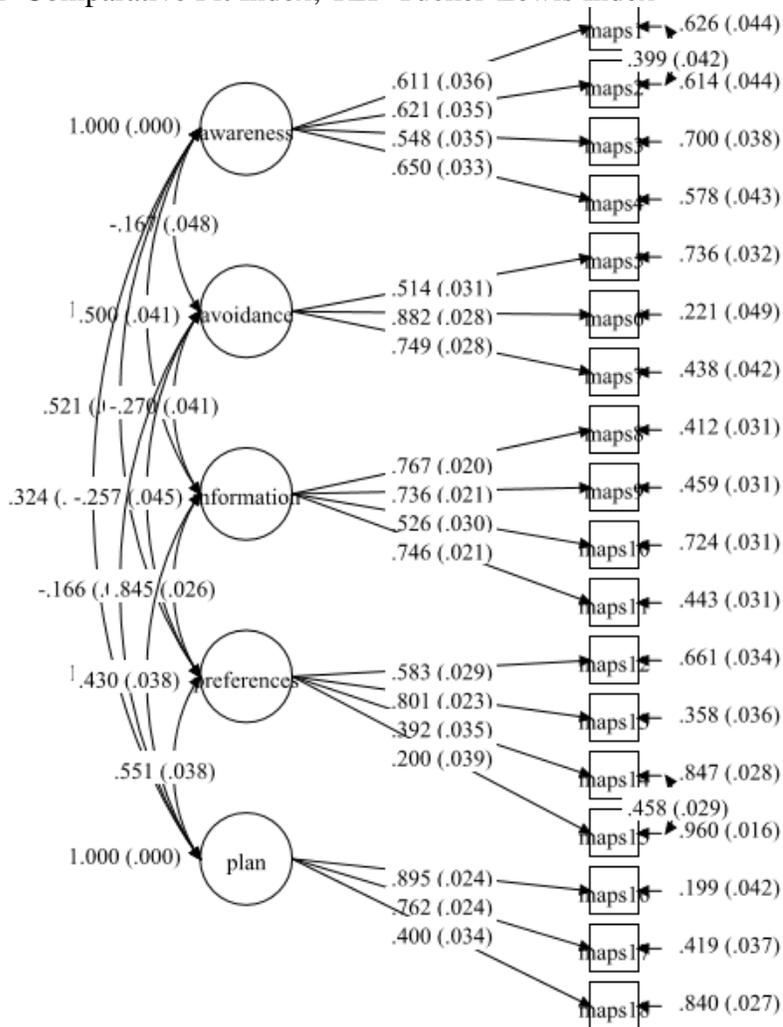


Figure 3. Model with Standardized Parameter Estimates of Confirmatory Factor Analysis in College Student Sample.

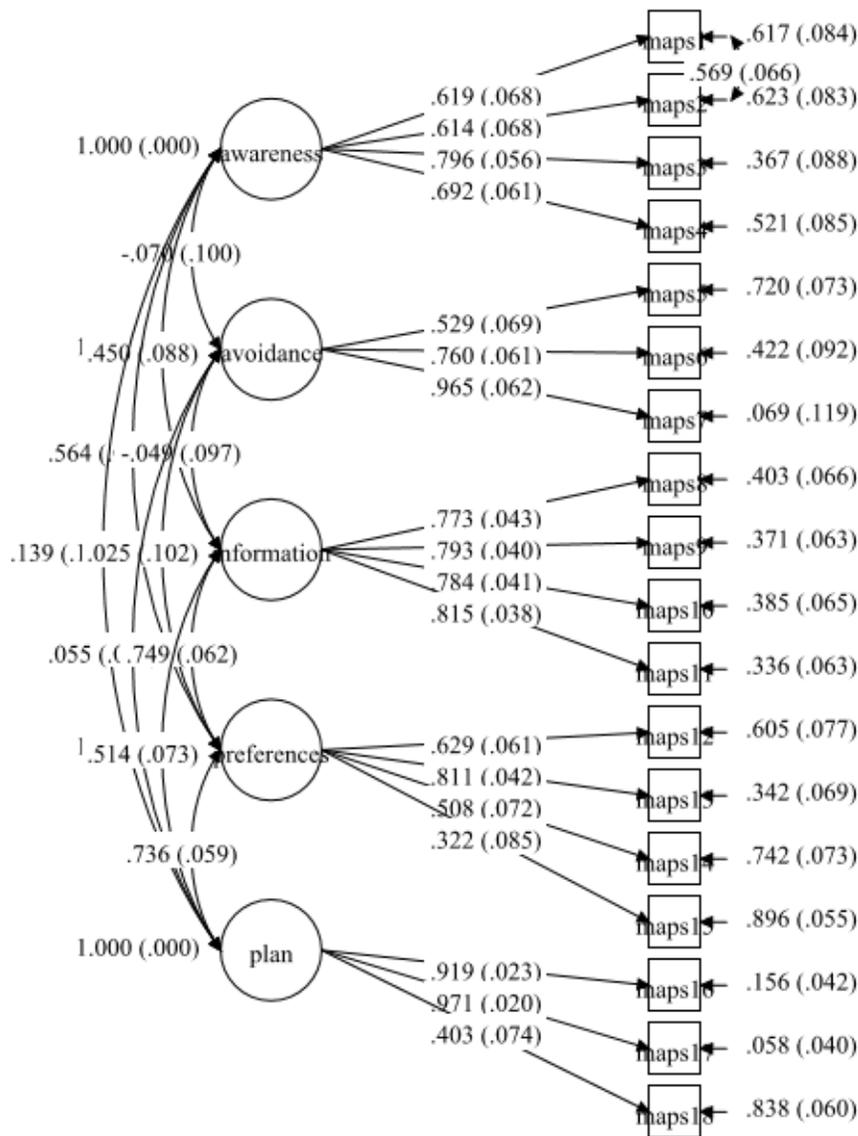


Figure 4. Model with Standardized Parameter Estimates of Confirmatory Factor Analysis in CNA Sample.

Validity of MAPS

Scores were examined via ANOVAs with post-hoc comparisons (due to unequal variances, Games-Howell was chosen) in both groups, across the MAPS measure, to examine the hypothesis that individuals would report the highest scores in earlier subscales, and lower scores in later subscales, as would be predicted by the TTM. For College students, the overall model was significant (Welch's $F(4,1926.63)=486.37, p<.001$). Likewise, for CNA's, the model

Table 4.

Games-Howell Post Hoc Comparisons between Subtest Scores by Group

	Mean Difference (Std. Error)		Mean Difference (Std. Error)
College Students		CNAs	
<i>Awareness:</i>		<i>Awareness:</i>	
Avoidance	1.45(.04)**	Avoidance	1.39(.13)**
Gathering Info	1.14(.04)**	Gathering Info	.76(.12)**
Dev. Preferences	.52(.04)**	Dev. Preferences	.26(.10)
Concrete Plan.	1.58(.04)**	Concrete Plan.	.98(.12)**
<i>Avoidance:</i>		<i>Avoidance:</i>	
Gathering Info	-.32(.05)**	Gathering Info	-.63(.14)**
Dev. Preferences	-.94(.04)**	Dev. Preferences	-1.13(.13)**
Concrete Plan.	.12(.04)	Concrete Plan.	-.41(.15)*
<i>Gathering Info:</i>		<i>Gathering Info:</i>	
Dev. Preferences	-.61(.04)	Dev. Preferences	-.50(.12)**
Concrete Plan.	.44(.04)**	Concrete Plan.	.22(.14)
<i>Dev. Preferences:</i>		<i>Dev. Preferences:</i>	
Concrete Plan.	-1.05(.04)**	Concrete Plan.	.72(.12)88

*p<.05; **p<.001

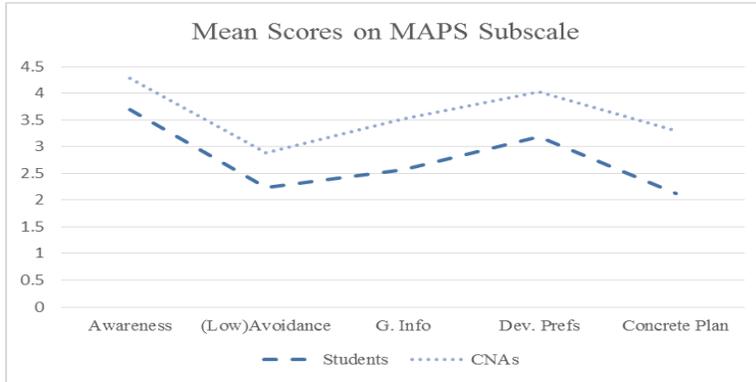


Figure 5. Mean Scores on MAPS Subscales between Samples

reached statistical significance (Welch’s $F(4, 338.770)=41.24, p<.001$). Given significance of the overall models, post-hoc comparisons were examined to pinpoint the source of differences. As demonstrated in Figure 5 and Table 4, neither group followed the hypothesized pattern entirely. While both groups reported their highest scores in the Awareness subscale, it was only statistically highest among the college student sample ($p<.001$). In the CNA sample, Awareness

scores were highest when compared with Avoidance ($p < .001$), Gathering Information ($p < .001$), and Concrete Planning ($p < .001$) but were not statistically different from their scores in Developing Preferences ($p = .06$). Also somewhat inconsistent with hypotheses, college students reported their lowest scores in Avoidance (reverse scored such that lower scores reflect higher avoidance) and Concrete Planning, which were not statistically different from one another ($p = .07$). For CNAs, lowest scores were reported in Avoidance ($p < .05$; scored such that lower scores represented more avoidance). Therefore, CNAs reported the “least readiness” for future care planning in their report of avoidance toward future care topics. Developing Preferences, although hypothesized to be correlated with a later stage of behavior change, was CNAs’ second highest reported subscale and not statistically different from their highest mean scores in Awareness. Students demonstrated a similar pattern, with Developing Preferences being their second highest subscale, statistically higher than Gathering Information ($p < .001$), avoidance ($p < .001$), and Concrete Planning ($p < .001$).

Comparing the two groups to one another on the MAPS subscales via ANOVA (Table 3) revealed support for our hypothesis that CNAs would report more developed attitudes across the measure than will the college student sample. Only two subscales, Awareness and Developing Preferences, did not violate assumptions of homogeneity of variance; for other subscales, the Welch F statistic was used which is robust to violations of this assumption. Compared to college students, CNAs reported more awareness of future care needs ($F(1, 908) = 58.22, p < .001$), less avoidance of future care topics (Welch’s $F(1, 162.87) = 33.95, p < .001$), had gathered more information (Welch’s $F(1, 169.35) = 90.14, p < .001$), showed more developed preferences ($F(1, 908) = 127.69, p < .001$), and engaged in more concrete planning (Welch’s

F(1,161.95)=119.87, $p<.001$). Overall, CNAs scored significantly higher on the MAPS (Welch's F(1,175.14)=206.40, $p<.001$).

Table 5. Comparison of Mean Scores on MAPS Subscales

	N	Mean (SD)	F
Awareness			
CNAs	138	4.28(.81)	58.22**
Students	772	3.70(.82)	
Avoidance*			
CNAs	138	2.89(1.24)	33.95**
Students	772	2.24(.89)	
G. Information			
CNAs	138	3.52(1.12)	90.14**
Students	772	2.57(.89)	
Dev. Preferences			
CNAs	138	4.02(.81)	127.69**
Students	772	3.18(.80)	
Concrete Plan.			
CNAs	137	3.30(1.20)	119.87**
Students	772	2.13(.86)	
Total MAPS			
CNAs	138	3.60(.64)	206.40**
Students	772	2.77(.55)	

*Avoidance subscale reverse scored, such that higher values reflect lower reported avoidance.

** $p<.001$

Finally, bivariate correlations were used to examine the hypothesis that college student participants who endorsed more exposure to death would also report higher scores across the MAPS measure. Self-reported greater personal exposure to death was significantly related to greater scores in four of the five subscales including Awareness ($r=.11$, $p<.01$), Gathering Information ($r=.09$, $p<.05$), Developing Preferences ($r=.08$, $p<.05$), and Concrete Planning ($r=.09$, $p<.05$). Total MAPS scores were also significantly correlated with personal death exposure ($r=.12$, $p<.01$) Furthermore, self-reported death exposure in the form of having worked

in a nursing home was significantly correlated with higher scores on the Developing Preferences subscale ($r=.10$, $p<.05$). However, the Avoidance subscale failed to show a significant relationship with death exposure ($r=.03$, $p=.44$).

Study 1 Discussion

The present study served as the first step in examination of the MAPS measure, developed via CBPR methodology from its parent measure (PFC), in two independent samples: 772 college students, and 138 Certified Nursing Assistants (CNAs). In a series of confirmatory factor analysis models, the MAPS demonstrated acceptable to close fit of the hypothesized five-factor structure. As expected, based on the differences in sample size and their impact on the fit statistics, the model demonstrated better fit in the college student sample. However, it still reached acceptable standards in the much smaller CNA sample.

Given shortcomings with the current approach to advance care planning, some individuals have called for new, process based approaches such as those based in the Transtheoretical Model (TTM; Prochaska & Velicer, 1997). According to this model, changes in behavior (e.g., decisions regarding advance care planning), are the result of a progression through multiple psychological and behavioral phases beginning with pre-contemplation and moving through contemplation, preparation, action, and maintenance. Overall, the examination of the MAPS with regards to its basis in the TTM demonstrated variable support. As would be predicted by the TTM, the Awareness subscale did show the most development in both groups, but was only statistically higher than all other subscales in the college student sample. This may have been due to the larger sample size (and therefore power) in the college student sample. Later, action-based stages such as concrete planning were not necessarily the least developed, as predicted, such as in the case of the CNA sample where the avoidance subscale showed the least

development. In other words, CNAs still demonstrate avoidant patterns of behavior when it comes to future care planning whereas the expectation may be that due to their death exposure they may be less avoidant of future planning. This may be consistent with previous research showing that occupational exposure to death produced more negative attitudes about death, thus leading to feelings of avoidance toward considering future care (Chen et al., 2006; DePaola, Neimeyer, Lupfer, & Fiedler, 1992; Grant & Wade-Benzoni, 2009; Thorson & Powell, 1996). An alternative hypothesis to the differential functioning of avoidance is that it measures more of a personality-level variable than an attitudinal-level one (see below).

Consistent with the TTM, and a priori hypotheses, in the college student sample the concrete planning subscale demonstrated the least development, with avoidance coming in second to last. Concrete Planning, the subscale measuring the extent to which an individual has translated their potential preferences into “action,” for example by writing down instructions for the type of care they would or would not want, is the subscale showing the least developed attitudes in 18-year old college students. This makes sense, given the stage of life of the population, and the low likelihood they would be aware of advance care planning options.

Somewhat unexpectedly, both CNAs and college students reported lower scores in the Gathering Information subscale than in the Developing Preferences subscale. An assumption in the design of the measure was that respondents would have necessarily gathered information before having developed preferences, or made concrete plans, about their future care. In practice, it seems that individuals do not feel such a prerequisite exists. A hypothesis for this finding could be that individuals are gathering information (i.e., through experiential processes such as awareness of their own physical changes, or watching loved ones age and die) in ways that are not captured by items on the subscale. It could also be due to decisions having been made via

emotional (versus logical) processes, which may be untapped by the current MAPS measure (Bechara, Damasio, & Damasio, 2003). Further research would need to be done concerning the nature of this pattern to determine more definitely what accounts for the lower scores on the Gathering Information subscale.

The MAPS showed promising validity in producing significantly lower scores across the five subscales in the college student sample, compared to the CNA sample. As would be predicted given differences in both age (Pollack, Morhaim, & Williams, 2010), and experience with the care needs of older adults (Steinhauser et al, 2000), CNAs reported more awareness of future care needs, less avoidance of such topics, higher gathering of information, more developed preferences, and more concrete plans. This lends support for the measure's ability to meaningfully detect differences between samples in the development of their future care preferences and advance care planning.

Similarly, students who had been exposed to more instances of death in their personal lives reported more advance care planning, except in the case of the avoidance subscale. This may, again, suggest that avoidance is measuring a personality variable rather than a stage of change. Further development of the MAPS measure should examine the degree to which the avoidance items overlap with general measures of avoidance. However, the preliminary finding that college students who have more personal experience with death scored higher on four of the five subscales again lends support toward the measure's ability to detect such differences in attitudes. Furthermore, in the college student sample, working in a nursing home was related to more developed preferences, but not any other subscales. This may suggest the importance of firsthand engagement in experiential processes for moving earlier contemplation stages into action stages. This may prove to be a potential opportunity for intervention, in order to increase

motivation and willingness to engage in considering how one's values and goals influence future healthcare decisions. In fact, so called "simulation experiences," or opportunities for individuals to "try on" decisions and see how they play out," have been shown to be successful in training healthcare providers to improve patient care (Brannan, White, & Bezanson, 2008; Gaba, 2004; Medley & Horne, 2005; Robinson & Dearmon, 2013). Similar simulation experience could be designed related to hypothetical future healthcare situations, and demonstrate the process of making decisions for self or significant others.

STUDY 2: A QUALITATIVE EXAMINATION OF CNAS AS END-OF-LIFE CAREGIVERS: “THAT’S THE BEGINNING OF YOUR JOB; YOU’VE GOT TO CARE FOR THIS PERSON.”

The work of Certified Nursing Assistants (CNAs) accounts for at least 80% of the direct-to-resident care in nursing homes. CNAs are in charge of helping residents perform a range of everyday tasks (e.g., activities of daily living such as bathing, toileting, eating, dressing and grooming), with the average CNA spending two and a half hours caring for a given resident per day (Dawson & Surpin, 2001; Institute of Medicine, 2004; Nursing Home Compare, 2016). CNAs also represent the highest proportion of staff at a typical skilled nursing home facility (usually accounting for at least 60% of the staff), and the profession is projected to grow at a rate much higher than the average job growth over the next decade (American Health Care Association, 2011; Bureau of Labor Statistics, 2016). In a time when nursing homes are becoming de facto settings for end-of-life caregiving (Abbey, Froggat, Parker, & Abbey, 2006), CNAs represent a vital population to study for researchers interested in improving the dying process for nursing home residents and their families, as well as the caregiving experience for paid staff.

Certified Nursing Assistants and Resident Death

Currently, in the United States, anywhere between 24% and 35% of nursing home residents will die there, with another 37% being transferred to a hospital prior to death, after spending some of their final days in a nursing home setting (Day, 2016; Porock et al., 2005). Given the frequency and nature of their contacts with residents, CNAs bear the highest risk for exposure to death of all nursing home employees. Considering the extent of their occupational

death exposure, then, it is unsurprising that CNAs are those most affected by resident deaths (Braun, Cheang, & Shigeta, 2005; Schell & Kayser-Jones, 2007; Rickerson et al., 2005). CNAs forge close relationships with residents (Moss et al., 2003), and may be forced to quickly move on to the next “assignment” after a resident’s passing (Moss et al., 2003), establishing both literal and figurative constraints around the potential grief experienced by CNAs. The emotional and psychological result of these constraints has been called “disenfranchised grief,” by some researchers (Doka, 2002), which highlights the potentially damaging experience of grief occurring in an environment where it is not acknowledged (i.e., a professional workplace). Indeed, research has shown that disenfranchised grief is associated with negative personal outcomes for CNAs following the deaths of residents (Anderson & Gaugler, 2007).

CNAs face numerous challenges related to providing end-of-life care for dying residents. Foremost among these challenges is the nature of the job as fast-paced and task-oriented. CNAs are typically assigned a number of specific residents whose total care is their primary responsibility for a given timeframe, though they may assist with other residents’ care as well. While a CNA’s work is usually difficult, it becomes increasingly challenging at end of life, when care needed by individuals can be unpredictable, demanding, and time-consuming (Allen, Burgio, Fisher, Hardin & Shuster, 2005; National Institute on Aging, 2012). In a 2007 qualitative study on the topic, one CNA reflected on the distinct challenges of maintaining high quality end-of-life care when assigned “eight or nine” residents: “You finish your work, but you can't provide the care” (Schnell & Kayser-Jones, 2007). In addition to time constraints, CNAs are tasked with providing end-of-life care after receiving limited training overall, with sometimes absent training on end-of-life specific issues (Ersek, Kraybill, & Hansberry, 2000; Katz, Sidell, & Komaromy, 2000). Finally, power differentials across staffing levels (i.e., RN, LPN, CNA)

can provide an additional challenge to CNAs attempting to respond to the end-of-life needs of residents. Relationships among these levels of staff are often strained, with CNAs feeling disrespected and voiceless compared to their higher paid counterparts (Lopez, 2006). Indeed, research has shown a significant impact of improved communication between CNAs and higher level staff on end-of-life care outcomes (Zheng & Temkin-Greener, 2010).

Role Duality

The CNA end-of-life caregiving experience is hallmarked by ambivalence and duality. In their role as professionals, CNAs are encouraged to maintain a polite, professional distance from residents, such as employees in a customer service oriented position. Certainly this distance aids CNAs' efforts in engaging in care that is highly physical (i.e., "body work" such as turning residents) and occasionally at odds with the will of the resident. Simultaneously, however, CNAs are told to care for residents as if they were members of their own family (Dodson & Zinzavage, 2007; Hanson et al., 2002; Lopez, 2007), and residents report valuing authentic relationships with nursing home staff (Bowers, Fibich, & Jacobson, 2001). This conflicting message situates CNAs in a precarious space, forcing them to learn to code-switch seamlessly between languages of professionalism and kinship. This duality may be increasingly difficult to navigate during end-of-life caregiving, when there is a shift in the "professional" caregiving tasks required (e.g., changes in eating and drinking, increased calling out due to pain) as well as increased demands for personal, relational caregiving (e.g., sitting with residents, talking to residents, holding a resident's hand).

The proscribed, top-down-enforced professionalism often present in traditional nursing home settings can lead to coerced, emotional labor, which puts CNAs at risk for a host of negative outcomes (Lopez, 2006). In an extensive, naturalistic observation study of nursing

homes along the continuum from traditional to culture change (i.e., Eden Homes), Lopez (2006) observed the danger in managerial proscriptions of professionalism with regard to a CNAs emotional health:

This version of professionalism [impressed upon CNAs] thus required the caregiver to act as the uncomplaining target of rather unpleasant and abusive behavior by patients who dealt with their—very real—frustrations about declining health and control over their daily lives by taking their anger out on the caregiver CNAs.

Suppression of authentic workplace emotions in the service of professionalism may be even greater for African American CNAs, who face additional, often indirect, restrictions around expressing any negative emotions (Wingfield, 2010). Certainly these factors are at play in an exponentially greater rate in a Southern setting, with sizeable generational gaps between patients and paid staff, who are disproportionately African American.

Despite the undeniable importance of their “professional” responsibilities, it is these ostensibly “nonprofessional” aspects of the work of a CNA, including developing relational bonds with residents, which are often inextricably linked to their ability to complete other job-related tasks. Consider, for example, the importance of a trusting, personal relationship with a resident experiencing disorientation when trying to complete continence care. In fact, when asked, nursing home residents identify this relationship between themselves and CNAs as an incredibly important aspect of the care they pay for in a nursing home, equal to care in more traditional forms (e.g., help with ADLs; Bowers et al., 2001). For their part, CNAs view the quality of care they provide as determined by their relationships with residents (Bowers, Esmond, & Jacobson, 2000).

Current Study

As outlined, CNAs experience a high degree of exposure to death. In addition, their work-related tasks are enmeshed in duality, explicit and implicit restrictions on authentic

emotional experiences, and a lack of training underscored by a hierarchical sense of disrespect as a member of the “nursing home team.” Thus, the current study sought to understand the role of resident death for CNAs, and to inquire about improvements that might be made in nursing homes. Given that so little is known about their bereavement, and the complex issues at play regarding the topic, qualitative data was gathered via small focus groups and individual interviews at the facilities.

Study 2 Methods

Study 2 Procedures

The current qualitative analyses are part of a larger mixed-method project, in which data for both parts of the project was collected in tandem. Prior to any data collection, nursing home administrators from each of the facilities were contacted and asked to meet in order to obtain letters of support. During this meeting, the purpose and procedures of the study were explained and administrators had an opportunity to ask questions. After IRB approval, the study was advertised to potential participants via IRB-approved flyers in areas visible to staff members (e.g., staff break rooms, nurse’s station) and by word of mouth. Some facilities made announcements to staff to inform them of the study; in these cases, research staff made an extra effort to be clear that the study was entirely voluntary and in no way required of them by their employer. CNAs who were interested in participating in the qualitative interviews were given a consent form asking for them only to mark a box indicating they had read the consent and agreed to be audio recorded. This was due to the potentially sensitive nature of being audio recorded (more identifiable than written remarks) and the comments they might want to make (i.e., potentially of a critical nature of their place of employment). Owing to this added concern for

confidentiality, specific demographics were not recorded. Instead, RAs present for data collection recorded a general report of participants who engaged in the focus groups. CNAs were interviewed in person at their place of employment and offered snacks provided by the researchers as a thank you for their time.

The main goal of the qualitative interviews was to discuss the question, “What is it like caring for residents at the end of life?” CNA participants were asked to call to mind specific residents who had passed away, and guided by several prompts (Appendix E) to help ground responses in lived experience. Interviews were facilitated by the advanced graduate student principal investigator (PI), and approximately half were observed by one senior undergraduate RA (GL).

Study 2 Data Analysis

Data from the interviews were audio recorded, and subsequently transcribed by a professional medical transcriptionist hired for the project. Data analysis methodology included a primarily descriptive approach (Sandelowski, 2000), which has been identified as the best approach for qualitative data of the present kind, where “straight descriptions” of experiences are warranted. Furthermore, numerical presentations of themes (i.e., counts) are presented where appropriate, in order to provide a clear and accurate sense of the level of saturation of themes. Such numerical accounts of data are presented in order to avoid misleading (e.g., percentages) counts; also avoided are counts without context (i.e., example quotations), as such has been noted to decrease the validity of qualitative methodology (Sandelowski, 2000). Best standards of qualitative methodology have been previously defined in terms of “[rigor], credibility, trustworthiness, and believability” (Russell & Gregory, 2003). The present analysis sought to embody those standards in the following ways. As described below, coders sought to examine

reflexivity (i.e., the preconceived notions, beliefs, attitudes coders bring to the process of coding) both during individual coding (e.g., by taking process notes) and during group coding meetings by disclosing these biases. Thus, the coding team sought to increase both credibility and confirmability by engaging in self-reflection and explicitly noting how their personal contexts may affect the coding experience (reported below; Lincoln & Guba, 1985; Russell & Gregory, 2003). Furthermore, through triangulation (Sandelowski, 1995), specifically by assigning each transcript to be reviewed by three individuals, individual differences in interpretations of data were kept to a minimum, and reconciled throughout the process of data analysis. Whenever possible, quotations are presented in the results section to allow readers to form their own conclusions, and to enhance transparency. Finally, notes were taken during group coding meetings to document the analysis process (Bradley, Curry, & Kelly, 2007).

Coding Team

Five individuals participated on the coding team, including two senior undergraduate RAs (GL and AS), two graduate students (DD and MKE) and one faculty member (RSA). Prior to this set of analyses, two coders reported no prior qualitative data analysis (GL and AS), one coder reported one prior qualitative analysis experience (DD), one coder reported multiple previous qualitative coding experience (MKE) and one coder reported extensive previous experiences, including specialized training in qualitative methodology (RSA). The more advanced coders (MKE and RSA) were involved in deep coding of all 13 transcripts. The undergraduate coders provided coding on four transcripts each, and the graduate student coder (DD) provided coding on five transcripts. Thus, each transcript was coded by three individuals, including the more advanced coders (MKE and RSA), and one less advanced coder (GL, AS, or DD).

To enhance the credibility and confirmability of the present analyses (Lincoln & Guba, 1985; Russell & Gregory, 2003), all coders were asked to report on prior experience with 1) nursing homes and, 2) personal loss. Regarding nursing home experience, both undergraduate coders reported minimal exposure. One coder (GL) reported visiting a grandparent in a nursing home. The other undergraduate coder (AS) reported volunteering in the fall of 2015 in a rehabilitation facility associated with a local nursing home. One coder (DD) reported experiencing nursing homes both personally, by visiting grandparents, and professionally, by volunteering as a counselor in training, during her lifetime. The advanced graduate coder (MKE) reported volunteering in a number of nursing homes throughout her lifetime, including nursing homes in the Southeast as well as the Midwest, as well as seeing clients for therapy in nursing home settings. The faculty coder reported extensive (20 years) research, intervention/therapy, and personal experience in nursing homes.

One undergraduate coder (GL) reported relatively little personal loss. She disclosed losses of grandparents and great-grandparents, as well as some “health scares” for her father which the coder reported encouraged her to “examine her feelings regarding loss.” The other undergraduate coder (AS) reported “above average exposure to loss” for her age. She reported experiencing the death of her maternal and paternal grandparents, being specifically affected by the loss of her paternal grandfather during middle school whom she identified as her best friend. She also reported the loss of her mother and grandmother in the same week during high school. This coder reported views of death including “a sense of inevitability” and is aware of the potential “negativity” this brings to her coding. The less advanced graduate coder (DD) reported relatively little personal, familial loss, except that of a grandfather during her teens. She reported loss of “other distant relatives” in addition. Moreover, this coder reflected more on her

professional experiences related to death, including time spent working in a hospice/palliative care facility. This coder reflected on death “as inevitable, but a test of a person’s acceptance and contentment with their life.” The more advanced graduate coder (MKE) reported personal loss including grandparents and grandparents-in-law. This coder also reported working in professional environments including hospice and palliative care in which loss was normative and discussed openly. The faculty coder reported personal loss including parents, serving as primary caregiver and executor for each, a close sibling, and several other relatives. She also reported extensive professional experience working in palliative care and hospice settings with individuals and family members near the end of life.

In addition to these disclosures, coders were asked to use personal memoing as a method to note where personal biases may be influencing the analysis of the data (Groenewald, 2008). In such cases, memos were discussed with the other coders in order to help parse out emerging content vs. coder-specific lenses. Although previous qualitative researchers have utilized bracketing as a method by which to ameliorate the impact of personal attitudes on the coding process (Gearing, 2004), the present investigators reject the idea as difficult if not impossible to accomplish. Rather, the personal lenses through which data is coded can be useful (e.g., in the event of a cultural experience that helps make sense of a participant’s language) and should not be altogether discounted.

Coding Process

The process of coding was recorded in notes taken during two group coding meetings, as well as notes taken by individual coders throughout the coding process, in order to increase transparency. Process notes from the first group coding meeting revolved around a theme of inexperience for the more novice coders, with notes including “Is what I am coding legitimate?,”

“Am I coding too much or too little?,” “Is this subjective?,” “second guessing,” and “lack of structure compared to quantitative work.” From the more advanced novice coder (the first year graduate student), process notes also included the “richness” of qualitative data and impression that “the medium of the data capture more than would be possible in quantitative form.” On the part of the more advanced coders, some process notes from the first meeting included “bubbling up” of realizations about the unique role end of life plays for CNAs, whereby their nonmedicalized, human contact is of greatest importance; in contrast, the role of the RN at the end of life may decline in importance. The faculty coder expressed “surprise” at herself for not realizing that CNAs sometimes find resident bodies themselves, noting “I should have known that but I didn’t.” On one content piece, regarding CNAs discussing unpleasant (“hateful”) residents, the novice coders expressed “surprise” and never having encountered the idea of an unpleasant or difficult resident; in contrast, the more advance coders did not note surprise at this.

Notes from the second coding meeting focused more on the process of resolving and finalizing codes. However, the novice coders both expressed a shift in their experiences of coding the second round of transcripts. One coder (GL) felt themes in her second two transcripts were harder to distill, while another coder (AS) felt her transcripts contained less rich content than her first two. The less advanced graduate coder (DD) noted her transcripts were much richer than her first two, but noted having to avoid inserting her own “confirmation bias” to seek out themes continuous from the last coding session.

Study 2 Results

Thirty-five CNAs participated in 13 brief, qualitative interviews. Specific demographic information was not collected from participants in order to encourage a sense of complete confidentiality and promote honesty in responding (e.g., in questions about institutional policies

and workplace environment). However, process notes from the field revealed the sample was entirely female, 33 of the participants were African American (2 Caucasian) and participants seemed to range in age from mid-20's to early 60's. Interviews were transcribed by a professional medical transcriptionist and coded as noted above. Major themes and subthemes emerged regarding the experience of CNAs as end-of-life caregivers and are discussed below.

Appraisals of Death

When asked broadly about their experiences with dying residents in the facilities, many CNAs discussed appraisals related to death. Table 6 gives a summary of death appraisal statements under major themes of *death as a negative event* (N=9), *death as a neutral event* (N=9), and *death as a positive event* (N=5). Subthemes emerged under *death as a negative event* including *death as sad/difficult* (N=5), *fear of death* (N=2), and *unpredictability of death* (N=2). Under the major theme of *death as a positive event*, subthemes emerged including *death as a release from suffering* (N=3), and *death as God's plan* (N=1).

Death as a Process

CNAs sometimes spoke about the actual process of death itself, commenting on symptoms (e.g., residents stop eating, talk about “meeting their maker,” hallucinate, increased falls). One CNA spoke about her experience noticing a familiar progression: “...it was kinda like a shock because she just, you know, started going down, stopped eating, and you know, we know the tail end to that story when they start doing that, most of the time.” Other CNAs discussed the progression of death for residents feeling quick, such as the experience of this CNA: “And you know, all of a sudden they're up good and they get—you know, all of a sudden they just turn for the worse (finger snap).” Another CNA described an experience with a resident death that felt

unpredictable: “But, um—well, yeah, it was unexpected, but anyway, he had started doing things a little different, though.”

Table 6.

Major Theme: Appraisals of Death

Negative Appraisals	Neutral Appraisals	Positive Appraisals
<p>Subtheme: Fear Like, I don't wanna get old, but ...since I've worked here, I just ...it's like it's scary and you wanna—like, you hope that someone's here to hold your hand and take care of your kids, stuff like that. It's scary, though. It's scary. Scary to me.</p>	<p>But for the most part, it's just a part of life and it's an appointment that no one can miss and no one cannot take. So, that's the way I look at it.</p>	<p>Subtheme: Release from suffering Death is not as hard as it should be—as it's known to be. It's actually a good thing...Because that way you're going on and you're not suffering ...</p>
<p>Subtheme: Sad/difficult Sometimes it's really sad for me, um...you know, seeing a resident—um, I have seen 'em, you know, when I come in, you know—every day. You know, they walk—some of 'em are walking around and talking and doing normal stuff, and then all of a sudden there's a big change.</p>	<p>But you get used to it, you kinda learn. You kinda learn that, um ...that that's why most of 'em come here...you know, to die.</p>	<p>Subtheme: God's plan Yeah, it's sad, but at the same time you just have to realize that God has His own plan for each and every one of us...and you just have to follow in His guidelines. And as long as you step in the same line He wants you to, it won't be as hard as it normally would be if you didn't know that first.</p>
<p>Subtheme: Unpredictable You don't have to be old; sometimes young ones be in sad shape...Now you don't have to be old; it don't go by age now. ...We have more young ones come and leave than we do the old ones.</p>		<p>So, like I say, it's just an experience to be able to see it ... and it's heart-filling.</p>

Relationships with Residents

In addition to discussing their views on death, CNAs spoke frequently about the impact of working at the end of life with regards to their relationship with the residents they care for.

The major theme that emerged, *relationship with residents*, contained four subthemes including

Table 7.

Major Theme: Relationship with Residents

Attachment	Kinship	Frequency of Contact	Difficult Residents
Because when I first started, I was like, how do you get so close to these people? And then once you start working, you know, like . . . you can get really, really, really close to some of ‘em.	It’s just like a family member that actually died, and it hurts to your heart when you really get attached to ‘em, you know. . . So I try not—since the last one that broke my heart when she passed, I try not to get attached to ‘em, but it’s very hard not to, you know.	We just get used to everybody, get used to seeing ‘em, you know, around every day, you know, on a day-to-day basis and stuff like that. But it’s really still a good experience . . . because they make us laugh (laugh).	Or, you know, we run into some mean ones. We do, we run into some mean ones. And because they were so mean before they got into this situation, their family tends to not come as much.
Well, you know what, sometimes it’s hard because you work with ‘em so close. I work so close with them on a daily basis, so you get attached to ‘em. So it hurts sometimes...or something, that you start to love ‘em, you know what I'm talking about?	And some residents you get drawn to, and it’s like . . . it’s so hard for you because it’s like that’s your family member that’s . . . you know, that’s slowly passing away, you know.	And some of ‘em looking forward to seeing you. Some they’ll be like, “Where you been all day? Why didn’t you come in and see me?”	Some come in with attitude, you know, they don’t wanna be bothered, they don’t wanna talk to you.

attachment to residents (N=13), kinship/family-type relationships (N=12), everyday/frequency of contact with residents (N=10), and difficult residents (N=5). Examples of exemplar quotations from these subthemes appear in Table 7. As seen in the table, some overlap occurred between

these responses, but efforts were made to only code each statement with one subtheme under the same major theme.

The Space of Death: Inside and Outside the Facility

At each facility, CNAs were asked about funeral attendance policies. All CNAs agreed they were allowed to attend funerals of residents. When asked about her experience with workplace policy around funeral attendance, one CNA said “Yes, they would let you go and spend that time for you.... It really helps....For the resident’s family, they’re loving it. They love all that [inaudible]. We have attended a lot of funerals (laugh).”

When asked about discussions in the nursing home about death, CNAs had less positive experiences, with five CNAs outright noting they had never been asked or told about the death-related experiences of their job. One CNA noted, “I’m glad you asked the question, because it’s like nobody really never asks the CNAs, you know, how they really feel.” Another CNA expressed “No, I’m just a CNA...Mmm-mmm, you’re the first person that’ll listen.” Another participant expressed speaking with her fellow CNAs, but lacking a formal or private space to do so: “Well, we just meet in the break room (laugh)... We get somewhere, we talk.”

Regarding resident experiences of death, two CNAs noted a lack of space and suggested the facility develop a “bereavement area” for residents and their families at the end of life.

Elaborating on the idea, one participant noted:

I think like when—like if the facility really know when someone’s coming to the end of their death, I think they should just have a separate room, somewhere just for that particular person, you know. Because, you know, for family members that can come and—not have another roommate. That’s what I think, you know. Because some of the residents do have family members, and I think they should have a private area just for that.

The Rewarding Role as Caregiver

When discussing their role at the end of life, CNAs frequently described it as that of an interpersonal caregiver (N=5). One CNA contrasted the “right” and “wrong” reasons to be in the field:

That’s the beginning of your job; you’ve got to care for this person. You can’t just pass pills and think that’s all that’s going on—it’s not. You’ve got to actually care for someone. And a lot of people are in this job for the wrong reasons, and that’s why a lot of people end up on abuse lists, a lot of people end up losing their license for different things, misabusing it, abusing their license and abusing these patients’ medications. They’re in it for the wrong thing. I mean, because to tell you the truth, it don’t pay that good. It’s not really a top-paying job unless you’re a doctor. It’s really not.

Another CNA put it this way: “Just, like, you gotta have a good heart for this job. That’s the most important. You have to care. If you don’t care, don’t do it.” Four CNAs spoke specifically about “having a heart” for the job. One CNA saw her role as that of a joyful presence in a difficult time: “But, you know, I just want to bring some sunshine to some people who, you know, is not able to bring—you know, to live a fulfilled life, I just want to make somebody happy at their last . . . ending. You know?” Another participant described her role as comforter: “You know, you make ‘em feel as comfortable as possible, [as comfortable] as you can.”

CNAs spoke about the positive aspects of their job, as well. Three CNAs specifically described their job as rewarding. One participant noted “it’s sorta like a reward in that you was able to help someone, you know. . . . Because a lot of ‘em look forward to the CNAs coming, you know, every day.” Other CNAs described it more generally as “a good job.” One CNA spoke about the human connection being directly linked to rewarding aspects of her job:

Like, you’ll see somebody you know was mean as a rattlesnake, but now they’re humble... Because people change....And you could be the reason why that person changed. Because you was nice to them regardless of how mean they were to you. You was nice to them. And you might be the only person that they’re nice to, but the point that they was nice to you shows that something in them changed. They didn’t mean to do whatever it was that they did out there in their life, and they’re trying to make it better,

but their family won't give 'em a chance, so they're reaching out to you for that chance. I mean, being a CNA is really rewarding.

Duality/Ambivalence

The theme of duality/ambivalence appeared a number of times throughout the interviews, both explicitly and implicitly. Explicitly, CNAs spoke about the ways in which their CNA-selves and their human/person-selves were inexorably intertwined. This occurred in a number of ways, for example by the ambivalent connections they formed with residents:

Um . . . it's a good experience, but sometimes it's sad, like, you know, when you get to know people, you know, just as well as friends or anybody that you would get to know and you became friends with them. And, you know, it's all like a different kinda relationship with everybody.

It's hard to know that you're everything that they got and they intend on seeing you, but it also makes you feel good to know that when you get to work that this person's going to be so happy to see you that it's really just going to make their day.

Duality also appeared regarding the roles of CNAs, in balancing their closeness to residents and families of residents but also maintaining their identities as professional caregivers. For example, two CNAs expressed the following regarding attending resident funerals: "And we have went to some [funerals] that family didn't come, you know, it was all just us...No family members...You feel important...You feel important and you feel like you were their family and you had to go."

And you can talk to the families, but, you know, it's only . . . you can kinda soothe them and talk about different stuff, but you have to still kinda be . . . kinda cautious of what you say—because of the HIPAA violations and all that good stuff. . . . You could find yourself in trouble if you say too much, you know.

CNAs also discussed the difficulty of caregiving professionally and personally, noting the overlap of the two: "And then if you have to leave here—do eight hours and dealing with your workload and then having to go home and you have children to repeat it over, it's just maybe like in a faster pace. . ."

Two CNAs also discussed the impact, both personally and professionally, of having family members live in the facilities in which they worked:

I know my dad was here for the last years of his life. And it gives you a different perspective. If you've never had a family member that you have to totally let somebody be their caregiver, you don't understand what these people are going through (voice cracking, getting emotional). Because their life is in your hands (voice cracking, getting emotional).

It does. It changes your outlook. Because until you have an actual person that's a family member and . . . X's had her mom here for stays and stuff. And you don't realize everything that family goes through. You don't realize . . . you know, they're just . . . until you do that, they're just a family member that you're taking care of. But once you put your family member *in here*, then you look, well are they getting the care they need? You know, is their call light on too long, you know? Are people responding the way they need to? And of course you each have your own way of wanting them taken care of, you know. And it just changes. And then you think, well, number one, if there's a complaint about a resident, sometimes you can more sympathize on why that person is maybe complaining about that, you know. A lot of times they don't realize, you know, somebody's in another room giving a bath and it's gonna take longer for them to get the call light and different stuff like that. But it changes your outlook.

Another CNA discussed being reminded by a resident of her mom:

I remember the first lady I really got attached to. I was working 11 to 7, and . . . her and my mom were about the same age, they were *so* much alike even though, you know, there was no kin. And she really got to know me and my family, I really got to know her. And I remember when she was passing, I finally said, "Lord, I don't think I can handle it if I'm here when she passes." And she was really bad that last morning, and when I came in the next night [they were leaving with her], and I was like, "Thank you, Jesus." But you do. And it's not everyone. I mean, you love all of 'em and you care for all of 'em . . .but you get really close to some of 'em. Some of 'em really get to know you and really bond with you.

Implicitly, duality was noted when CNAs' responses to questions about their jobs as professional caregivers were met with answers about their personal caregiving, or personal losses. When asked about losing residents, one CNA mentioned the recent loss of both her sister and nephew.

Future Perspectives

As a direct result of their role as a CNA, many participants noted an impact on their views regarding their own future care, the future care of their loved ones, or death/dying in

general. One CNA expressed these concerns, “But then I would rather for somebody to be here [at the end of my life]. You know, I think about my kids, my family, and just even loved ones here.” For many CNAs, watching others die, made them think about their own future end of life:

Yeah, because like some of ‘em here, they pass, but they don’t have people out here with ‘em...And if you’re going by yourself, you don’t have anybody in the room with you to hold your hand or talk to you. So that makes me think about me too. I mean . . . what’s it gonna be like for me?

You talk about it all the time, you know, because you know, you always say, “Well, if I live to be their age, I don’t want this, I don’t want that.” Or sometimes we can see someone sitting up in the chair, I go, “I hope I live to be like her and I’m gonna be just like . . .” Am I gonna still be able to do this and hear this and see this? Because we have some still that are able to walk, talk, you know.

Some CNAs spoke about the impact of death exposure on how they viewed loved ones’ deaths:

But you know, it also helped me kinda understand, too, like my auntie just died and she was sick and she was hurting and she was in pain, and I understood more than my mom did. My mom is still, you know, like . . . she just wanted her *here*. But I know that she was suffering, and I know that it was better for her to go on. But like my mama, it’s her sister, and she’s having a hard time dealing with it. But I think because I work here, I kinda understand better, you know, that you don’t wanna prolong their life, have them living like this—living miserable. That’s just not what they want.

And it does, it was the same way with Daddy, because we had made decisions. I know Mother’s wishes, but I hadn’t ever really talked to Daddy about this. And so we had . . . I mean spur of the moment the doctor would walk in and say, “Do you want him on the ventilator? Do you want him on the BiPAP? Do you want him in ICU?” you know, “Do you want a tube back in?” And so it does . . . it makes you see the people who maybe have tubed somebody that’s just laying there, and they really don’t have somebody come in turning and drying ‘em . . . and stuff. And see, for me, I always told Mother, I said—because she told me, she says, “If I’m going to be myself, then do everything you can to get me back there. But if not, do not save me.” And I told her, I said, ‘Well Mother, I don’t know if I can do that. I don’t know if I can do that because I can go in and tell you I love you and kiss you and talk to you.’ But after you work here and you see somebody that’s in that stage, like what she said, it’s . . . it’s for you, it’s not for them.

One CNA spoke about the impact generally, of being surrounded by reminders of her own mortality:

You look at stuff different. A lot of stuff you took for granted then, you don’t take for granted now, because you never know what your situation will be like... And that makes

you think a lot about yourself and treating other people . . . the way you would want to be treated.

Limitations of Job

A number of CNAs noted ways in which they were limited, by time, staffing, or policy, in caring for their residents how they may have wished.

You would love to have less patients so you could spend more time with them one-on-one. But due to the way Medicare, Medicaid, and everything is set up, that's just not a possibility. Even not being able to take 'em outside.

Yeah, it's not all about, like, patient care work, like if you had less patients and stuff; it's like some patients like you just sitting there talking, and you're like, "I can't talk right now." They're like, "Well why?" and you're like, "Well, I've got 15 patients, and there ain't no way I can talk to you having 15 patients in eight hours."

And sometimes you have just like—I got a patient, she loves me coming in at 10 o'clock to watch *The View* with her, just watch *The View* with her. And some days I'm like, "I can't watch it today."

One CNA reported the limitations in a simple equation: "There's not enough staff. There's not enough CNAs. Some people gonna be cut short. And that affects the residents."

CNAs discussed ways in which they attempted to work around limitations to make time to care for their residents, with varying success:

And a lot of times I know . . . probably a lot of these ladies, too, you know, you [talk to 'em] on your lunch break, you go in there and sit and talk to 'em. They actually don't like you to do that. You know, they don't like you to really spend your lunch in with the residents.

But I have clocked out for the day. Because I promised one resident that I would come back and talk to her, so I had to clock out for the day and go back down and sit with her for a little while and talk to her. Because I hate to lie to her, tell her I'm coming back and don't go back.

CNAs also mentioned their pangs of responsibility when they are faced with limitations in their job:

Like I couldn't be one-on-one with that person like the person needed one-on-one... Because that's their last days, and you know...I'm not there to do that like I want to. ...I mean, especially like when you, you know, [grabbed] a good bond with a resident.

Well I felt very sad and, um— and that I could've done more for that person than what I did do. I did the best I could, but if I had done more, to make it more comfortable for them... something I didn't do that I probably could've did, but I was busy or something.

And then you do better with the next resident because you know how you did that resident... You try to make more time with the other resident, spend a little more time. ... a little more better than the other one, because you say, I couldn't do this for this one, but I *can* do this for this one.

Difficulty of CNA Work

Though not directly asked about the aspects of their jobs that are difficult, *CNA job difficulties* emerged as a major theme with three subthemes including *hierarchy* ($N=15$), *underpaid/undervalued* ($N=10$), and *lack of recognition/respect* ($N=8$).

CNAs described being underpaid and undervalued in the following ways:

And there's other places that really do recognize their CNAs. Like for CNA Week, we don't get nothing? I mean, you don't recognize us in no type of way? I mean, that's like a slap in the face, and you're the one who makes this facility run. I mean, really, it's a slap in the face. A lot of facilities do not appreciate their CNAs because . . . a lot of CNAs feel like—I've heard a lot of us say . . . they think because they done went to college and got all this that they are so above us, you know?

I mean, if the pay would be better and just sometimes just listen to [us] . . . let our opinions be heard. Because like you said, we work with 'em 90 percent of the time. And a lot of 'em, like maybe some of the RNs or maybe the people that like do the rooms, you know, determine who's in a room with each other, they hardly ever have any contact with 'em. ..So what's wrong with coming and asking the CNAs, you know, 'How do you feel about such-and-such being in a room together?' or 'Have you noticed anything?' They don't do any of that; they just go off of what they think.

And that's why I think a lot of people . . . you know, [think], Well, they just, you know, wipe you-know-what and all that stuff. But we actually do take care of 'em every day.

Closely related, CNAs also described ways in which they feel a lack of recognition in their role, and a general lack of respect. When asked how their job might be improved, one CNA noted wanting "Respect or something, maybe like we get more." Other CNAs spoke more at length about the issue:

We're not recognized until we need to come in and kinda save and help. Because I mean, there's not—you know, you have—once a year you have CNA Week. I'm like, really?

It doesn't have to be on a day-to-day because that's what we're here for and that's what we get paid for. But then at the same time too, it would be nice. You know, you only get recognition when it's CNA Week, once a year.

I think that they should get back the Employee of the Month. Yeah. That would help. You know, then show up a little bit of appreciation. Even though they do, at times they have, you know, like little stuff for us like barbecues and whatever. They have little stuff for us, but they need to get back the Employee of the Month. You know, that'd mean a whole lot.

And they need to tell you, you know, more often that you did a good job and a job well done. You know, it's just . . . words count more than you're expressing.... Or just say, 'Thank you for a job well done,' you know, *daily*. They can't even say thank you. You know, 'I appreciate everything y'all did today' (laugh).

Related to the disrespect and undervaluation the CNAs feel from their institutions, CNAs spoke specifically and often about an experienced disconnect between staffing levels, most often between that of nurses (RNs, LPNs) and CNAs:

You know, they sit behind a desk and they pass their pills and they're done. But that's not nursing. Nursing is caring for somebody. Like, we don't get to pass pills, but I'm pretty sure if y'all could let us pass pills, y'all would.... If we could pass it, if we could give shots and we could administer all this medication, y'all would sit back there and write stuff down. Because that's...I mean, that's really what y'all are doing.

I mean, we all here doing the same thing..., and if we could work together—things don't come together until the State's in the building or . . . I mean, I'm just being honest about it....It's not an everyday—the CNAs, the nurses, I mean everybody should be familiar with each other because it takes all of us to run this place. But it's kinda like . . . things don't come together or we don't work together until there's an issue or the State's coming.

CNA 1: And when you go to a nurse and say, 'There's something wrong with Miss . . . whatever. Morgan, whatever,' you know. But you know the residents. CNA 2: Or if you go to 'em, they kinda brush it off, you know. Because we're not LPNs, and they *know*.

CNAs also talked about the administration, and the disconnect between their roles and the roles of the CNAs. CNAs conceptualized their role as important, equally important to other staffing positions: "You know, CNAs are a big part of a building, you know, of a nursing home, you know." Another CNA contrasted her intimate caregiving role with, perhaps, the role of less-

involved staff: “I’m hands-on with ‘em....You know, I’m just not walking by going, ‘Good morning!’” Other CNAs spoke more at length about the issue:

The people at the top really don’t understand how important we are until we have to do something drastic like boycott or something. You know what I’m saying? They don’t really understand that your facility’s not gonna work without us. So you really should care for us a little more. Because when we leave, it shuts down. Nobody’s gonna come and do this. You’re not gonna come out of your office and turn and bathe a patient. You’re not gonna do it.

They don’t get it. They don’t get it. They appreciate being in their little offices. That’s what they appreciate. They’re appreciate their four- and five-figure checks a year, you know, they appreciate that. They don’t appreciate that we’re working for almost minimum wage and doing most of the work.

One CNA articulated multiple ways in which the job is challenging:

Being a CNA, it is not easy work. It is not easy work. I mean, some folks look at it from a different position, because if you work here, then you know it’s not easy work. Before I worked here I was like, “You ain’t doing nothing but babysitting a patient, you ain’t doing nothing but babysitting an old person, changing whatever mess-up.” But, not easy work. [Other CNA agreement] You got some patients that don’t turn. [Agreement] You got some that wanna fight you. You got some that just . . . I mean, you’re dealing with different emotions, you’re dealing with different personalities, and it is not easy. It’s not easy at all.

Institutional Factors

CNA participants expressed their experiences with institutional-level factors that both help and hinder their job experiences. CNAs expressed overall positive support from one another in all facilities:

Um . . . in most cases we get pretty good support. We’re able to talk to each other and, you know, sort things out about different care plans and different things for me to do to make things better. You also have the rain and the storm where you can’t talk.

Yeah. That’s, you know, a big part of teamwork. Because you know, when you work with a team, I think that you can handle a lot of situations more better as a team...than just being an individual. So it makes it better for all of us to work as a family also. You know, with each other. That way we can get all the same thing that we need with each other. You know, whether one of us is feeling more sadder or, you know, anything. So yeah, the team, I think, is the best thing that CNAs can always...rely on.

As far as helping, I haven't run into nothing that'll help us, but amongst ourselves we have prayer every morning...We pray every morning at nine o'clock, so ...if anyone need a special prayer, whoever praying, they say the special prayer for 'em. We just started that, but since we've been doing that, that helped me a lot dealing with things that go on at the job and out of the job... We done it as CNAs. And everyone who wanna come out can join us.

In one facility, one CNA noted feeling supported by not only her fellow CNAs, but also the administration and other staff: "The people who are in the office know how close we get to these people, and they know that we go through a grieving process when somebody that we've really gotten close with passes."

More frequently, however, CNAs described feeling unsupported by the administration in their attempts to connect meaningfully with their residents:

They don't care about you; they just care about . . . if their facility's running. You know, because if they don't have a certain amount of CNAs, certain amount of nurses, they get closed down. You know what I'm saying? It's about money, and that's what's gonna really end up hurting 'em in the long run. Because it's going to get to a point where somebody's gonna find another profession.

They stopped us from doing that. We used to clock out and go take lunch. Like if she wanna watch *The View* with her, if it's her break time, spend her break time in there. We can't do that anymore.

CNA 1: Mmm hmm. You will get attached. They tell us not to get attached. CNA 2: They say not to. You know, your human instinct, you will get attached. They tell us not to get attached...Because they're trying to spare your feelings and not getting so break down and emotional breakdown. So that's probably why they tell us not to get attached to 'em.

Study 2 Discussion

In small group, qualitative interviews regarding the experience of CNAs as end-of-life caregivers, themes emerged in two distinct but interrelated global areas: 1) CNAs' experiences with dying residents and death specifically; 2) the experiences of CNAs as employees and caregivers more generally. It is unsurprising that CNAs spoke about their role in the nursing home hierarchy, given the extensive previous literature citing the problematic structure of staff in

long term care facilities. Indeed, the dismissal and disrespect CNAs feel regarding their role among the hierarchy of staff is one of the most salient CNA experiences, and it is cited as the foremost reason they leave a facility (Bowers, Esmond, & Jacobson, 2003; Pennington, Scott, & Magilvy, 2003). For the sake of this discussion, however, the nature of these experiences will be examined insofar as they relate to novel, or less-explored, concepts such as end-of-life caregiving.

Experience of Death in Nursing Homes

A common overall appraisal of death was a neutral one, including statements suggesting death is “a part of life” and “part of the job.” CNAs also frequently appraised death as negative, either citing a fear of death, the sadness that accompanies death, or its unpredictability. Less frequently, CNAs expressed positive feelings about death couched in religious beliefs, or viewed as a release from pain and suffering. Whatever the valence of their statements, CNAs spoke of death as a common, everyday experience in some cases, supporting the concept of nursing homes as places of high occupational death exposure.

On the heels of the commonality of death were themes related to its lack of space in the facilities themselves. All CNAs reported that administration allowed them to attend funerals of residents, particularly if they had worked closely with residents or if family members invited them. CNAs even spoke about the ways in which the administration allowed them to change shifts to attend funerals, if needed. However, several CNAs expressed never talking about the topic of death, never having been asked about their experiences, and facility administration contacts each noted that death was “not really” or “not very much” a topic in any new employee trainings for CNAs. Two CNAs, during one of the interviews, discussed the lack of space for families and residents for “bereavement.” They thoughtfully suggested a dedicated space might

help residents and their families experience a better death, implicitly communicating the need for such a space for those who mourn. When asked about a space for their own bereavement, the CNAs laughed and noted that they use “the break room.” As noted in previous literature (e.g., Dodson & Zinzavage, 2007), death in these nursing homes seems to be swept under the rug—ever-present and impactful, but not important enough to have its own space inside the facility. The work of processing, or even acknowledging death seems to be lost in the hustle and bustle of the daily work of the CNA, though it is never truly far from her mind.

Impact of Relationships with Residents

Previous literature has highlighted the ways in which valuing their close relationships with residents is one way CNAs make meaning of a job in which they are constantly devalued and even abused (Pfefferle & Weinberg, 2008). Consistent with this, CNAs in the current sample overwhelmingly spoke of their close connections with residents. CNAs identified “attachment,” “close bonds,” and affection as the lynchpin between death and strong emotional reactions. CNAs frequently distinguished residents with whom they worked closely, frequently, and/or “got attached to” as those for whom end-of-life caregiving was most impactful. CNAs also noted some difficult or “hateful” residents, for whom caregiving is a greater challenge, but this was less common than reports of positive resident relationships. One CNA described her experience with a “mean” resident who changed in his behavior toward her, making meaning of their bond even in the context of a difficult resident.

Another common characterization of relationships with residents was that of “like family” or CNAs being the “only family” a given resident might have. This identification with residents as family is not new in the literature (Moss et al., 2003). In fact, Anderson et al. (2005) reported on the ways in which nursing assistants think about and respond to resident behavior,

concluding individuals used “mother wit” (i.e., treating residents as they would care for their own child) as well as “the golden rule” in their roles with nursing home residents. Both of these “mental models” of caregiving presuppose a close or familial relationship, or even personal substitution (e.g., treating a resident as you would want to be treated).

Role of Duality/Ambivalence

CNAs statements regarding the process of caring for residents at the end of life sometimes explicitly acknowledge a sense of ambivalence or duality. This occurred when acknowledging the sadness of a loss with the relief in an end to a resident’s suffering. It also occurred when expressing the rewarding feelings associated with the role of the CNA as being so important to residents, but also the difficulty to being pulled in various directions.

However, duality also was represented among the sometimes contradictory themes related to the role of CNA and her situation in the structure of the nursing home. Foremost among this duality was the role of CNA as a human, personal caregiver, with a close relationship to residents, who is simultaneously not acknowledged as an important resource in the resident care team. CNAs frequently commented on their role as caregivers “with heart,” acknowledging the authentic, human relationship necessitated by the role of CNA. Still, despite their knowledge of resident personalities, needs, and preferences, CNAs reported feeling “at the bottom of the totem pole,” “disrespected,” and unrecognized in their facilities. In the world of “patient-centered care,” CNAs seem to be the obvious center of caregiving and the most direct connection point between a facility and its residents. However, just the opposite was communicated by a number of CNAs, who feel as though other staff “don’t listen” or “don’t ask” for their input on care related tasks.

So called “culture change movements,” such as the Green House, in the long term care industry have reorganized the traditional nursing home along these lines, including changing the role of nursing assistants to a more holistic and autonomous care provider. Culture change homes demonstrate a host of increasingly positive outcomes for resident care (Kane, Lum, Cutler, Degenholtz, & Yu, 2007). Interestingly, in addition to positive changes for residents living in culture change homes, CNA-equivalents in these homes experience less staff turnover and increased autonomy in their roles as caregivers (Rabig et al., 2006).

Duality also appears in the way in which CNAs recognized the intersection of their personal and professional identities. As might be expected in a job in which part of the managerial expectation is the use of personal emotions (e.g., compassion, caring, empathy) in the process of caregiving, CNAs expressed overlap between their personhood and their role as CNA. For example, CNAs expressed staying after “clocking out” to talk with residents because they were limited in time during their shift. CNAs also expressed frustrations with policy-level dictates that they should separate their “work emotions” from “personal emotions,” such as being prohibited from spending their lunch breaks watching TV with a resident who requested it.

In a particularly interesting exchange, two CNAs discussed attending resident funerals. As a result of attending, and being among the only attendees at the service, one CNA reflected that she felt “important” and “like you were the family” in that role. Another CNA, however, commented on the restrictions in what they are allowed to say to family members, noting a need to be “kinda cautious,” owing to HIPAA regulations. The intersection between mourning alongside family members, with whom some CNAs personally identify as well, and restricting what you might say as to follow privacy regulations certainly has the potential to produce a high level of ambivalence.

Following logically from these connections between the personal and professional identities, CNAs also commented on being reminded of personal, nonwork related relationships through working with their residents. One CNA spoke about the ways in which having her father in the facility also changed her perspective on caregiving for her residents, noting an increased sense of connection with family who “put their lives in our hands.” One CNA also discussed being reminded by a dying patient of her own mother, highlighting the salience of the duality across personal and professional spheres.

CNAs experience, also, the impact of their work with residents at the end of life on their personal views about death, future care, and the experiences of their loved ones. CNAs generally agreed that working with people who routinely die increased their own awareness of their mortality, and potential future care options: “I don’t want this, I don’t want that.” Another CNA phrased it as an imperative to “making preparations.” In addition to their own future care, CNAs spoke about preferring less aggressive care for their loved ones at the end of their lives as a result of witnessing the slow decline and low quality of life of residents in their facilities. This is consistent with some recent interventions utilizing videos to demonstrate the reality of end-of-life situations, hypothesized to make these scenarios “real” for individuals completing advance directives (El-Jawahri et al., 2010; Volandes et al., 2009). In addition, although much of the advance care planning literature cites findings suggesting that African American individuals prefer more aggressive medical interventions, newer literature suggests that differences are more precisely due to differences in health literacy. One study found that when provided with a short video, no significant racial differences existed in end-of-life care preferences (Volandes et al., 2008). Perhaps for the CNAs witnessing the reality of end-of-life care in their nursing homes, the same process is occurring to shift their attitudes and preferences.

Understaffed and Under Staff

Finally, CNAs discussed the difficulties in balancing their important role as caregiver with their high workload and limited support. CNAs spoke with some guilt and a sense of responsibility or obligation regarding wanting to do more, spend more time, generally provide better care for residents, yet feeling limited by their time and staffing constraints. CNAs also expressed limitations in the degree to which they were able to collaborate with the staff “above them” in the nursing home hierarchy, including LPNs and RNs. CNAs expressed “not being beneath anyone,” with the implicit suggestion that they are treated as if they are.

CNAs’ desires to provide more one-on-one time care to residents is particularly relevant when, as one CNA put it, “that’s their last days.” At the end of life, interpersonal care becomes more and more relevant, with CNAs being poised to provide such care on the strong foundation of their intimate knowledge of resident needs and preferences. Yet, CNAs feel ignored and disrespected by those who could be in the position to change such a system.

Study 2 Conclusion

CNAs from four Tuscaloosa skilled nursing facilities provided their experiences as end-of-life caregivers via focus groups and qualitative interviews. CNAs in the current sample expressed death being a common experience in their jobs, and varied on their attitudes toward death. CNAs overwhelmingly expressed positive, meaningful relationships with residents, and that the more meaningful the relationship, the harder the loss. CNAs reported limited ways in which they are acknowledged as important caregivers, and denied having been previously asked about their experiences with death of residents. CNAs desire to do more for residents than regulations and staffing/time allow, and end-of-life care provides an ideal opportunity for the interpersonal caregiving strengths of CNAs to shine. Such an opportunity would likely increase

resident quality of care, dying process, and bereavement outcomes for CNAs and families.

However, in the current system, CNAs find it challenging to operate in their de facto role as end-of-life caregivers, instead focusing on doing “what you can.”

STUDY 3: THE IMPACT OF DEATH EXPOSURE ON CERTIFIED NURSING ASSISTANTS: RELATIONSHIP WITH DEATH ATTITUDES, COMPASSION FATIGUE, AND ADVANCE CARE PLANNING ATTITUDES

Most people regard death as unpleasant, and most are able to avoid reminders of death in their everyday lives. However, some individuals are unable to escape exposure to death because their jobs or life experience require it. These individuals have been hypothesized to experience “vicarious traumatization” transferred via their suffering patients (McCann & Pearlman, 1990; Robinson, 2010). Individuals such as those employed in long term care settings are inundated not only with potentially traumatic experiences, but daily reminders of their own mortality. Overall, research has been too neglectful of the importance of this population in studies on death exposure (Anderson & Gaugler, 2007). However, researchers have long examined the population of funeral directors in this realm, generally showing weak negative relationships between death exposure and fear of death (Harrawood, White, & Bernshoff, 2008; Linley & Joseph, 2005). Historically, literature shows a discordant array of findings more broadly, some suggesting that greater exposure promotes higher anxiety (DePaola et al., 1992; Grant & Wade-Benzoni, 2009; Thorson & Powell, 1996), some finding the opposite (Lester, Getty, & Kneisl, 1974; Yeaworth et al., 1974; Schell & Zingler, 1984), and some finding no correlation at all (Keith, 1996). Studies that examine populations more similar to CNAs, for example nursing students, have found that more experienced nursing students report greater death anxiety compared to less experienced students (Chen et al., 2006), while other studies report the opposite (Aradilla-Herrero et al., 2013). A recent review synthesizing research on death anxiety in nurses concluded that younger

nurses display greater anxiety and more negative attitudes toward caring for dying patients compared to their older counterparts (Peters et al., 2013a).

Given this discrepant body of findings, combined with the growing need to understand the impact of death exposure on staff in long term care settings, the current study examines the impact of death exposure on CNAs in the Southeastern United States. Specifically, we are interested in the relationship between death exposure, both personal and professional, and death attitudes, both positive and negative. We seek to extend previous examinations of these constructs by examining two potential moderators of the relationship: experiential avoidance and behavioral inhibition. Finally, we move a step further and examine the relationship between death exposure and two relevant outcomes for CNAs: compassion fatigue and attitudes toward future care. Again, we examine these relationships in light of a potential moderator: negative death attitudes.

Death Anxiety

Death anxiety is the term given to the sense of fear, worry and/or apprehension as a result of awareness of one's own mortality, nonexistence of the self, death, or dying, whether real or imagined (Lehto & Stein, 2009; Wong, Recker, & Gesser, 2004). The fear of death assumed to underlie death anxiety refers to an "emotional reaction involving subjective feelings of unpleasantness" as a result of thinking about any of several aspects of death (Hoelter, 1979). In cultures that place a high value on medical care, death anxiety may be more pronounced, owing to emphasis on life preservation (Meliones, 2000). Furthermore, death anxiety refers to both an implicit and explicit fear process because of its unconscious root to the evolutionary struggle for survival (Panksepp, 1998) as well as its link to a consciously experienced fear response (Lehto & Stein, 2009).

Although it is hypothesized to be a universal experience, three antecedents to death anxiety have been outlined including stressful environments, life-threatening illness/event, or exposure to death/dying (Lehto & Stein, 2009). Relevant to the current examination is the lattermost antecedent, which has been shown to produce varying outcomes. For example, grief resultant from the death of a grandparent has been linked to increased death anxiety in adolescents (Ens & Bond, 2007). Yet hospice nurses, who experience a high dose of death exposure, consistently report lower death anxiety than other nurses, perhaps owing to training and educational opportunities (Payne, Dean, & Kalus, 1998; Zyga, Malliarou, & Lavdaniti, 2011).

Like other experiences that instigate an attempt at self-regulation (i.e., to decrease the negative emotion associated with it), maintaining defenses against the unpleasant experience of death anxiety has been shown to require self-control and is subject to fatigue in experimental paradigms (Gaillot, Schmeichel, & Baumeister, 2006) as well as individuals employed in death-relevant fields, such as nursing home care, oncology, and funeral services, over time (Lattanner & Hayslip, 1985). Thus, it is plausible to wonder about the effects of long-term exposure to death salient stimuli (e.g., CNAs working for years with dying residents). Yet, other studies have identified a greater amount of death anxiety in younger long-term care staff compared to older staff (Peters et al., 2013a; Robbins, Lloyd, Carpenter, & Bender, 1992).

Perhaps the explanation lies in a proposed developmental progression of death anxiety: an initial spike during the 20s followed by a decline and a second spike during the 50s (Russac, Gatliff, Reece, & Spottswood, 2007). Interestingly, Russac and colleagues (2007) only demonstrated the second burst of death anxiety in women but not men. Possible explanations for a developmental progression of death anxiety include increased exposure over a lifespan or

greater grappling with the developmental task of death acceptance leading to decreased anxiety in older age (Kastenbaum, 2000; Neimeyer, 1988), and/or threats to reproductively-related values leading to greater anxiety during the height of reproductive fertility (Russac et al., 2007). The curious second spike of anxiety shown in women during their 50s has been speculated to be related to the reminder of aging imposed by the onset of menopause, on average around age 51 (Hvas & Gannik, 2008; National Institute on Aging, 2013).

Theoretical Framework

As reviewed above, death exposure has been shown to increase, decrease, or have no effect on death attitudes such as fear, anxiety, and acceptance. What accounts for the set of discordant findings? A possible answer lies in a moderating variable: avoidance (Figure 6). Based on basic behavioral principles of operant conditioning, it is likely that the extent to which

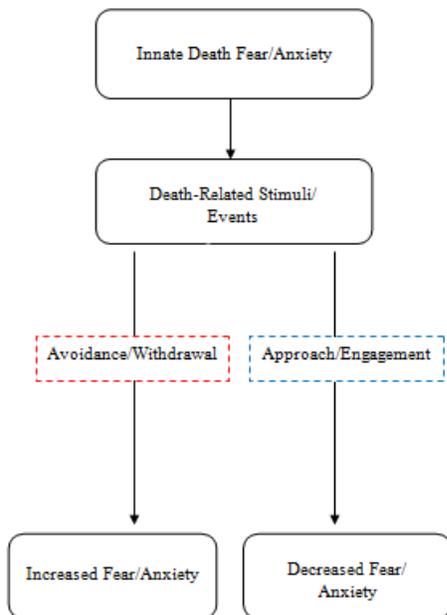


Figure 6. Impact of avoidance/approach on death anxiety

death exposure impacts subsequent anxiety depends on the degree to which the exposed individual engages with processes that are at work in the extreme (e.g., phobias), more mild and even normative anxiety can be maintained and subsequently heightened through refusal to engage with a feared stimulus.

For example, consider the case of an individual with anxiety related to elevators. If the individual is able to avoid riding on elevators (e.g., she works on a low floor in her office building) then they have no reason to become less afraid of elevators. In fact, they may even increase their fear by an automatic reaction (e.g., increased heart rate and thinking, “Those things are deadly”) every time they see someone get on an elevator. By quickly removing themselves from the feared stimulus, before their anxiety decreases, they continue in their fear associations: elevator=fearful; no elevator=safe. On the other hand, an individual with the same fear, but who works on the 70th floor, is now nearly required to ride the elevator. If that individual rides the elevator enough times, even though they fear it, their fear will decrease over time due to habituation. In the case of the present study, CNAs may have little choice to disengage with dying residents, but very well may disengage with resultant thoughts and feelings, effectively choosing to avoid exposure. In line with this logic, more recent work suggests that the extent to which repeated occupational exposure to death produces negative outcomes is moderated by personality variables such as avoidance and greater fearful attitudes toward death (Linley & Joseph, 2005). Halliday and Boughton (2008) similarly demonstrated a moderating effect of death experience on death anxiety, but their methods preclude causal inferences owing to a quasi-experimental design.

Research on the construct of *experiential avoidance/psychological flexibility* suggests a promising route to measure an individual’s likelihood of engaging with anxiety-provoking

stimuli instead of engaging in avoidance (and subsequent fear reinforcement). Though the construct is hypothesized to engender aspects of both experiential avoidance and psychological flexibility, “experiential avoidance” will be used for the sake of simplicity in the following discussion. Experiential avoidance refers to an individual’s unwillingness to engage with experiences that produce negative internal reactions, for example unpleasant thoughts, emotions, or physiological sensations (Hayes et al., 2004; Hayes, Wilson, Gifford, Follette, & Strosahl, 1996). Experiential avoidance has long been hypothesized to be relevant to death anxiety and decreasing such avoidance is a goal in existential therapy (e.g., Yalom, 1980). It has also been shown to be a useful puzzle piece to explain models of reinforcement and maladaptive behavior (Chapman, Gratz, & Brown, 2006; Kashdan, Barrios, Forsyth, & Steger, 2006; Newman & Llara, 2011). Even when other individual characteristics are controlled for, experiential avoidance has been able to meaningfully predict a host of mental health problems as well as moderate the effectiveness of treatment (Bond, Hayes, & Barnes-Holmes, 2006; Lillis, Hayes, & Levin, 2011; Tull, Gratz, Salters, & Roemer, 2004).

Alternatively, *behavioral inhibition* may provide another route to measuring an individual’s likelihood of suppressing, rather than engaging with, unpleasant reminders of death. Behavioral inhibition evolved from the Reinforcement Sensitivity Theory and is considered an underlying system whereby aversive stimuli are regulated (Gray, 1987). For some researchers, behavioral inhibition has been described as a syndrome beginning in childhood that presents as extreme shyness, social withdrawal, and fear of new situations (Turner, Biedel, & Wolff, 1996). The present study utilizes the construct of behavioral inhibition more continuously, acknowledging that individuals demonstrate behavioral inhibition to varying degrees (Carver & White, 1994). Researchers who study the impact of personality-level behavioral inhibition via

self-report measures believe that they measure, in most part, neuroticism or a “negative reactivity super-factor” (Jorm et al., 1998).

Behavioral inhibition and experiential avoidance, then, are hypothesized to be related yet distinct constructs. Thus, while behavioral inhibition may measure a predisposition to attend and react to threatening stimuli, experiential avoidance measures a tendency to disengage from processing such experiences. Studies have demonstrated experimentally that maladaptive reactions to anxiety-provoking stimuli likely presuppose experiential avoidance in combination with behavioral inhibition sensitivity (Maack, Tull, & Gratz, 2012; Pickett, Bardeen, & Orcutt, 2011). Given the limited research on the relationship between these two constructs and their potential moderation of death experience on death attitudes, both will be explored in the present study.

Terror Management Theory

The prevailing sense of fear aversion associated with death is both adaptive and inevitable; however, it is also maladaptive to be paralyzed by the sense of our human mortality. Therefore, we develop self-regulatory defenses against such anxiety. Though it has not been examined in relation to the set of variables in the current study, Terror Management Theory (TMT) is one of the most comprehensive and researched theories that propose how humans avoid a constant reality of paralyzing fear in the face of their own finite nature and any project dealing with fear of death would be remiss to avoid mention of it. TMT proposes that humans exist in a unique tension: on the one hand, striving for survival with all the species of animals on earth, but on the other hand, singularly aware of our fleeting existence (Greenberg, Pyszczynski, & Solomon, 1986). Within this tension exists anxiety and TMT posits that humans seek to reduce that anxiety through one of several methods of believing that a part of themselves will

continue beyond their physical life (Rosenblatt et al., 1989). This sense of immortality includes both literal and symbolic beliefs. For example, belief in the idea of an afterlife or heaven would constitute a literal immortality belief, while belief that one's accomplishments will outlive them would be a symbolic immortality. Therefore, two common defense mechanisms are associated with TMT: cultural worldviews (e.g., heaven, religious beliefs) and self-esteem/personal valuation (e.g., belief in one's contributions to the world).

TMT is a controversial theory, explored almost entirely in experimental and quasi-experimental (vs. applied) settings, and has been challenged by several researchers (Kirkpatrick & Navarette, 2006; Navarette & Fessler, 2005; Leary & Schreindorfer, 1997). Yet some data supports its basic tenets. Overall, many studies highlight the ways in which individuals with lower self-esteem possess less resistance to mortality salience cues (Gaillot, Schmeichel, & Maner, 2007; Goldenberg & Shackelford, 2005; Harmon-Jones et al., 1997; Kashima, Halloran, Yuki, & Kashima, 2004; Taubman-Ben-Ari & Findler, 2005; Taubman-Ben-Ari & Noy, 2010). Likewise, Schmeichel and colleagues (2009) showed that individuals higher in implicit self-esteem tend to engage in less worldview defense following mortality salience. However, a handful of studies refute these findings (Landau & Greenberg, 2006; McGregor & Jordan, 2007; Taubman-Ben-Ari & Findler, 2006). Notably, self-esteem is often manipulated experimentally and not much is known about the ecological and external validity of self-esteem as a predictor of death anxiety. Furthermore, most studies utilize American college students as participants (mean age of 22), which likely makes the findings narrow in generalizability (Burke, Martens, & Faucher, 2010).

Researchers have looked more extensively at the cultural worldview tenet of the theory, finding support that reminding individuals of death increases the importance of religious reading

material (Norenzayan & Hansen, 2006), strength of belief in the afterlife (Schoenrade, 1989), and participants' beliefs in specific religious teachings (e.g., the dominion of man over the natural world; Goldenberg et al., 2001). Some work specifies more precise ways in which cultural worldviews offer protection. For example, Jonas and Fischer (2006) found in a series of experiments that only individuals who are vested intrinsically in their religious beliefs derive benefits from them. Relevant to the current study, CNAs in the Southern United States are likely to endorse strong intrinsic religious beliefs which may impact their relationship with death anxiety. TMT would predict that CNAs would be in a cyclic process of religiosity, whereby intrinsic religious beliefs would prompt defense mechanisms against mortality salience, and mortality salience (e.g., working with a dying resident) would activate religious beliefs. Owing to this complicated relationship and historical evidence of statistically significant correlations with death attitudes, religiosity will be controlled for in the study.

TMT provides an important model for linking the experiences of nursing home staff to mortality salience threats. As would be predicted by TMT, recent research has highlighted the ways in which simply interacting with older adults proves threatening to younger adults (i.e., by activating ideas about death and thus defense mechanisms against resultant anxiety; Nelson, 2005; Martens, Goldenberg, & Greenberg, 2005). Furthermore, the extent to which we are able to employ ageism to protect ourselves against internalizing the inevitability of aging and deterioration has been proposed as common mechanism of self-preservation (Bodner, Shira, Bergman, Cohen-Fridel, & Grossman, 2015; Nelson, 2005). Indeed, research has shown that viewing older faces (vs. younger ones) primes an individual to respond with death-relevant words (vs. neutral ones), suggesting that simply interacting with the aged brings to mind ideas of death (Martens, Greenberg, Schimel, & Landau, 2004). Older studies have shown that nursing

home staff who report more negative feelings about death also report more negative attitudes toward aging, older adults, and discussion of death (Eakes, 1985; DePaola, Neimeyer, & Ross, 1994; Vickio & Cavanaugh, 1985).

Project Model

The present study proposes to examine several specific relationships as outlined in the section below on goals and hypotheses. However, owing to the complex nature of relationships between the constructs previously examined, a hypothesized model is presented to facilitate clarity. Figure 7, below, shows how death attitudes are proposed to exist in a web of factors. For example, it is generally assumed that death anxiety discourages many individuals from engaging in advance care planning and as few as 18-38% of Americans engage in end-of-life care planning at all (Allen, Eichorst, & Oliver, 2013; Benson & Aldrich, 2012). But it is possible that engagement with high rates of exposure to death would serve to either increase or decrease avoidance, making individuals such as CNAs statistically different in their willingness to engage in advance care planning than individuals with no occupational death exposure. Behavioral principles would again suggest that repeated exposure combined with a tendency of engagement (vs. avoidance/inhibition) would seek to decrease death anxiety through partial extinction of the fear response, while repeated exposure coupled with high avoidance would predict the opposite. Thus, in the proposed model, experiential avoidance/behavioral inhibition acts as a moderator on the relationship between death exposure and death attitudes, which in turn influence attitudes toward future care and compassion fatigue.

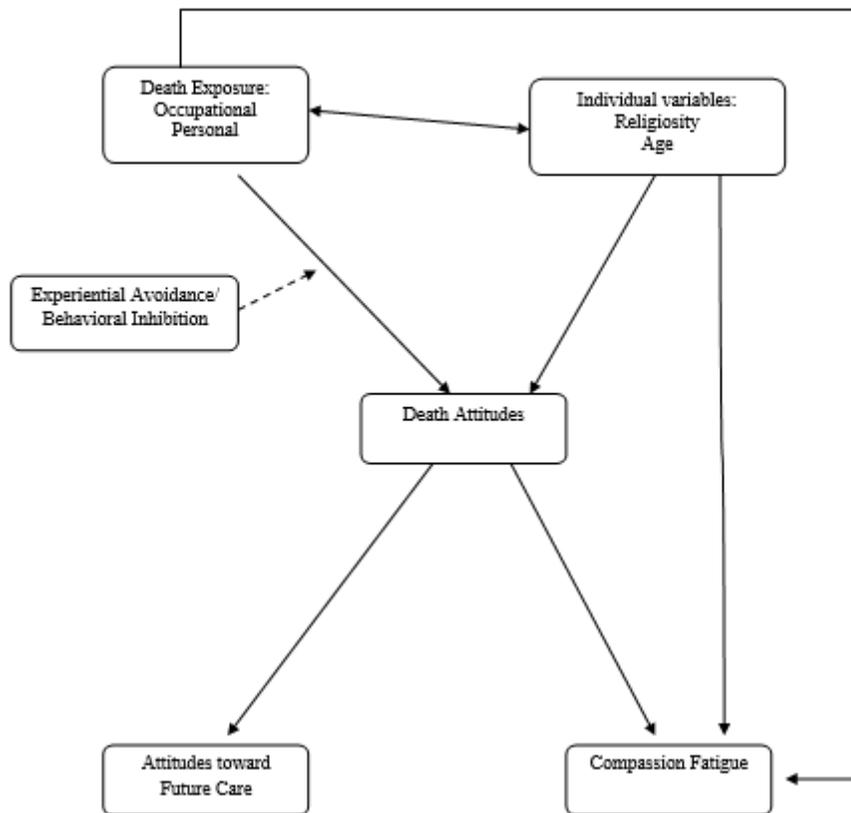


Figure 7. Project Model of Relationships among Variables

Need for Study

The present study seeks to understand bereavement and death exposure within a population of CNAs. Furthermore, the present study seeks to move beyond prior work by examining the relationship between these issues and moderating variables such as avoidance tendencies. Finally, the present study extends the literature by going a step further, considering how these variables relate to associated attitudes and actions (i.e., regarding preparation for one's own future care needs and compassion fatigue). By better understanding the intersections of these complex topics, quality of care for residents may be improved through more effective staff support programs and policies in the nursing home facility. Furthermore, this study is one of the

few to examine a reason for the discrepant findings related to death exposure and may provide direction for future theoretical and applied research in the area of occupational death exposure.

Goals and Hypotheses

Specific aims for the current study include the following: (a) to understand the relationship between death exposure and death attitudes; (b) to understand the role of experiential avoidance and behavioral inhibition as potential moderators between death exposure and death attitudes; and (c) to explore the relationship between death attitudes and preparation for future care and compassion fatigue.

We hypothesize: (a) experiential avoidance/behavioral inhibition will moderate the relationship between exposure to death and negative death attitudes (e.g., fear of death, death avoidance), such that for those with greater avoidance/inhibition scores greater exposure will predict greater negative attitudes, whereas for those with less avoidance/inhibition, greater exposure to death will predict less negative attitudes (Figures 8 and 9); (b) negative death attitudes (e.g., fear of death, death avoidance) will be significantly predicted by overall less willingness to engage in preparation for future care, while positive death attitudes (acceptance) will be significantly predicted by overall greater willingness to engage in preparation for future care; and (c) death attitudes will mediate the relationship between death exposure and compassion fatigue.

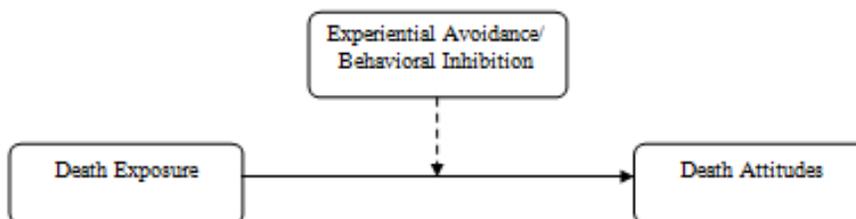


Figure 8. The proposed moderation of experiential avoidance/behavioral inhibition on the relationship between death exposure and death attitudes.

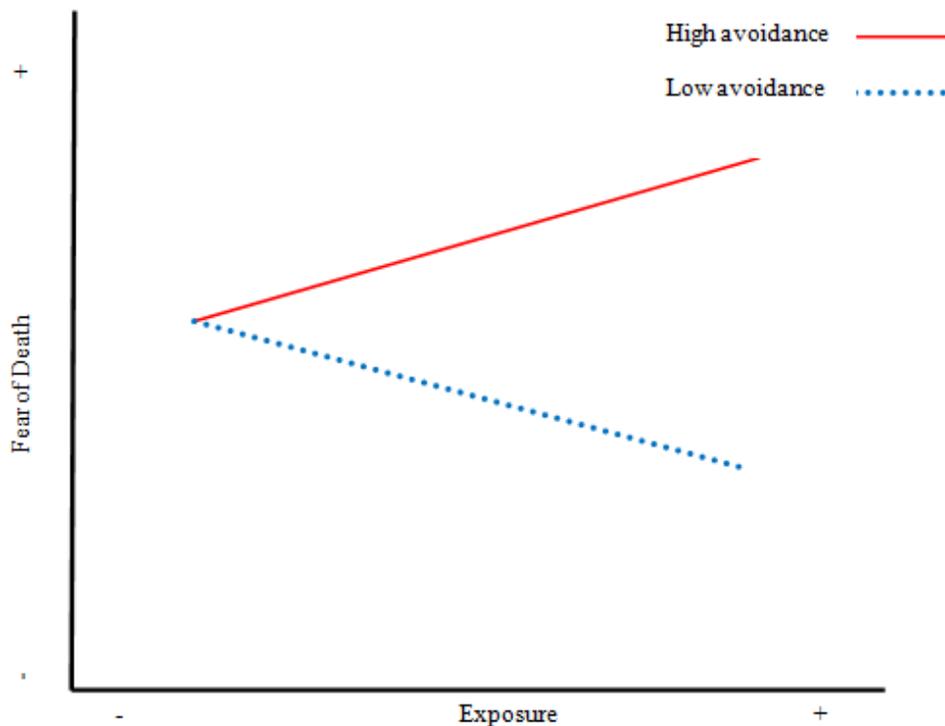


Figure 9. Example of proposed moderation on negative death attitudes

Study 3 Methods

Participants

Participants were 110 CNA staff from four skilled nursing facilities (SNF) in the Tuscaloosa (Park Manor, Hunter Creek, and Forrest Manor) and Birmingham (Fair Haven) area. All participants were CNAs in their facilities, and CNAs from all three shifts were represented (79.1% respondents from 1st shift; 20.9% from 2nd/3rd shift).

Study 3 Procedures

Prior to data collection, nursing home administrators from each of the facilities were contacted and asked to meet in order to obtain letters of support. During this meeting, the purpose and procedure of the study was explained and administrators had an opportunity to ask questions. After IRB-approval, the study was advertised to potential participants via IRB-

approved flyers in areas visible to staff members (e.g., staff break rooms, nurse's station) and word-of-mouth. Some facilities made announcements to staff to inform them of the study; in these cases, research staff made an extra effort to be clear that the study was entirely voluntary and in no way required of them by their employer.

All interested parties received an informed consent document describing the procedures and minimal potential risks (e.g., possible discomfort over presented topics, fatigue). Participants who voluntarily agreed to be in the study completed the consent and accompanying packet of surveys. Participants were encouraged to enjoy snacks provided by the research staff during or after completion of the surveys. After completion of the packet, participants were given \$5 and thanked for their time and efforts. Research assistants asked participants to sign a receipt acknowledging receipt of the \$5 (cash), and were told their signed receipts were kept separate from their survey answers.

Study 3 Measures

Demographic information regarding age, gender, race/ethnicity, religiosity (see below), marital status, and education was collected (Appendix F). Additional measures included the following.

Duke Religion Index (DUREL). The DUREL (Koenig, Parkerson, & Meador, 1997; Appendix G) was used to measure the demographic variable of religiosity. The measure contains five items and addresses organizational (e.g., attending church), nonorganizational (e.g., reading the Bible) and intrinsic (e.g., incorporation into daily life) aspects of religiousness (Koenig et al., 1997). The remaining three items were selected from Hoge's 10-item intrinsic scale (Hoge, 1972) to create a measure of intrinsic religiousness. Koenig et al. (1997) report a Cronbach's alpha of .75 for this scale and showed only moderate correlation with the two items measuring

different forms of religiousness. More recent research corroborates the reliability and validity of the measure (Koenig & Bussing, 2010; Storch, Strawser, & Storch, 2004). In the current sample, the measure reached acceptable internal consistency ($\alpha=.73$). The two items measuring different forms of religiousness (i.e., organized versus intrinsic) were significantly correlated at a medium effect size ($r=.45$, $p<.001$).

Death Attitude Profile-Revised (DAP-R). The DAP-R (Wong et al., 1994; Appendix H) is a 32-item survey measuring both positive and negative death attitudes along five confirmed factors including Fear of Death (seven items), Death Avoidance (five items), Neutral Acceptance (five items), Escape Acceptance (five items), and Approach Acceptance (10 items). Participants answer via seven-point Likert style response options ranging from “Strongly Agree” to “Strongly Disagree” with higher scores indicating greater endorsement on the scale (e.g., more death avoidance, more approach acceptance). This measure has been found to have good reliability ($\alpha = 0.65$ to 0.97), construct validity, and test-retest stability ($\alpha = 0.61$ to 0.95) over a 4-week time period (Wong et al., 1994). A more recent use of the measure in a population of oncology nurses also yielded acceptable reliability ($\alpha = 0.76$ to $.93$) except for the Neutral Acceptance subscale, yielding a value of $.42$ (Dunn, Otten, & Stephens, 2005). The DAP-R provides a more complete picture of death attitudes as opposed to one-dimensional scales (e.g., Templer’s Death Anxiety Scale) and multi-dimensional scales measuring only negative attitudes toward death (e.g., Multidimensional Fear of Death Scale). In the current sample, four of the subscales yielded at least acceptable to good internal consistency (Fear of Death $\alpha=.83$, Death Avoidance $\alpha=.81$, Escape Acceptance $\alpha=.76$, and Approach Acceptance $\alpha=.80$). As in previous research, the Neutral Acceptance subscale did not yield acceptable internal consistency ($\alpha=.40$). However, the

measure demonstrated good internal consistency when divided into Positive (Acceptance) Attitudes ($\alpha=.85$) and Negative (Fear/Avoidance) Attitudes ($\alpha=.89$).

Behavioral Inhibition System Scale (BIS). The BIS Scale (Carver & White, 1994; Appendix I) contains seven items assessing behavioral and affective responses to various statements, scored on a 4-point Likert style scale from “very true for me” to “very false for me.” The seven BIS items include statements such as “Criticism or scolding hurts me quite a bit” and “I worry about making mistakes.” Taken from the larger Behavioral Inhibition System/Behavioral Activation System Scales (BIS/BAS Scales), the BIS items comprise an independent scale of inhibition not dependent on the other items in the scale for psychometric validity (Ross, Millis, Bonebright, & Bailley, 2002). Internal consistency for the BIS scale is within acceptable range ($\alpha=.72$; Carver & White, 1994). Likewise, the scale has been shown to possess good discriminant validity (Carver & White, 1994; Gomez, Cooper, & Gomez, 2005). Owing to poor Cronbach’s alpha values in the pilot sample, items were minimally rephrased in order to allow each item to be anchored in the same direction (i.e., such that greater scores always indicated greater construct presence). Removing reverse scored items has been previously more successful in a CNA sample, according to the substantial experience of Dr. Parmelee. Indeed, the BIS achieved good internal consistency in the current sample ($\alpha=.83$).

The Acceptance and Action Questionnaire-II (AAQ-II). The AAQ-II (Bond et al., 2011; Appendix J) is a 7-item scale measuring experiential avoidance and psychological inflexibility. Respondents indicate their agreement with various statements on a 7-point Likert scale from “Never true” to “Always true,” with greater scores indicating greater levels of experiential avoidance. Examples of items from the scale include “Emotions cause problems in my life,” and “My thoughts and feelings do not get in the way of how I want to live my life.”

The AAQ-II has good psychometric properties including a mean alpha coefficient of $\alpha=.84$ across six samples (with the lowest $\alpha=.78$), 12-month test-retest reliability ($\alpha=.79$), and good convergent and discriminant validity (Bond et al., 2011). In the current sample, the scale demonstrated good internal consistency, with an alpha value of .90.

Compassion Fatigue Scale-Revised (CFS-R). The CFS-R (Adams, Boscarino, & Figley, 2006; Appendix K) is a 13-item scale measuring work-related stress and disillusionment related to caring professions, and includes both a Trauma (five items) and Burnout (eight items) factor. Trauma items include statements such as “I am losing sleep over a client’s traumatic experiences” and “I have suddenly and involuntarily recalled a frightening experience while working with a patient.” Burnout items include statements such as “I feel that I am a ‘failure’ at my work” and “I feel I am unsuccessful at separating my work from my personal life.” Respondents are asked to respond along a 10-point, visual analog Likert scale, with anchors of “Never/Rarely” and “Very Often.” Reliabilities are good for both the subscales (Trauma $\alpha=.80$; Burnout $\alpha=.90$) and the total scale ($\alpha=.90$; Adams et al., 2006). Furthermore, it was found to have good discriminant and convergent validity in a sample of social workers (Adams et al., 2006). In the current sample, both subscales reached acceptable internal consistency (Trauma $\alpha=.73$; Burnout $\alpha=.75$), with the whole scale having good reliability ($\alpha=.85$).

My Aging Preparation Scale (MAPS). The MAP Scale (unpublished, 2013; Appendix B) was developed based on the Preparation for Future Care Needs (Sorensen & Pinquart, 2001) and has yet to be tested in any population (beyond the present set of studies). Based on theoretical understanding of advance care planning, items measure the five latent constructs assessed in the original instrument (Awareness, Avoidance, Gathering Information, Developing Preferences, and Concrete Planning factors), while being more accessible to respondents (Flesh-

Kincaid Reading Level=3.6). As discussed in Study 1 of the current project, the 18-item measure was developed through collaboration with a Wisconsin-based community advisory board and several rounds of collaborative revision based on feedback. The MAPS measure demonstrated acceptable fit of the five-factor model, as well as initial validity/reliability statistics consistent with its proposed use (Study 1). In the current sample, the measure demonstrated good internal validity overall ($\alpha=.84$), with three subscales falling in the acceptable range (Awareness $\alpha=.83$, Avoidance $\alpha=.79$, and Concrete Planning $\alpha=.79$). One subscale fell in the excellent range (Gathering Information $\alpha=.90$), while one fell in the questionable range (Developing Preferences $\alpha=.67$).

Death Exposure. Owing to a lack of available measures in the literature, seven items were designed and used to measure a participant's subjective death exposure (Appendix L). Two items were included in the demographic section (Appendix F) and asked participants to simply estimate lifetime personal and work-related loss over the last six months. The other five items appeared as a coherent scale, with a visual-analog Likert (1=Not at all/almost none, 10=Very, very much). Items asked participants about "how much death" they had experienced in several areas including "your entire life," "when you were a child (less than 16 years old)," "while working as a CNA total" and over the last six months both "as a CNA" and personally (i.e., "NOT counting deaths at work"). As a unified scale, the five items measured on the Likert scale reached acceptable internal consistency ($\alpha=.76$).

Institutional Demographics. Nursing home staff (e.g., administrators, Directors of Nursing) were asked to provide institutional demographics (e.g., size of facility, number of staff) regarding their facility (Appendix M). Facility staff were also asked about the presence of formal support for staff including training, procedures, and interventions related to bereavement/end-of-

life care. These data were supplemented via public information available on the Medicare website (<http://www.medicare.gov/nursinghomecompare>).

Study 3 Data Analysis

Statistical analyses were conducted using IBM SPSS Version 22. Except when otherwise noted, data met assumptions required for statistical procedures (e.g., normality, collinearity). Analyses were conducted, and are presented, in the following order: 1) basic demographics characterizing both the sample of participants and the nursing home facilities in which they are employed; 2) exploration of the items used to assess death exposure; 3) regression models exploring the relationship between death exposure and attitudes. As noted above, the regression models examine the impact of death exposure on negative death attitudes moderated by both BIS (Regression 1) and AAQ-II (Regression 2), in addition to the impact of exposure on attitudes toward advance care planning, moderated by positive death attitudes (Regression 3), and the impact of exposure on CNA compassion fatigue, moderated by negative death attitudes (Regression 4). For regressions, missing data was treated with pairwise deletion, and listwise for all other analyses.

Study 3 Results

Participant demographics can be seen in Table 8. Participants were overwhelmingly female (98%) and African American (94%), consistent with the demographic make-up of CNAs in this geographic region. While the mean age was approximately 37 years old, participants ranged in age from 19 (N=3) to 64 (N=1), with 6 participants choosing not to disclose their age. The majority of participants identified as single (60.9%), with 25.5% identifying as married, 7.3% as partnered, 4.5% as divorced, and 1.8% as widowed. Of those who reported their highest completed education level (N=108), half (50%) reported having a high school diploma, 29.1%

reported attending “some college,” 7.3% reported attending “trade/vocational” training, 7.3% reported earning a G.E.D., and 4.5% reported having a 2-year degree.

Table 8.

Participant Demographics						
	N	Age Mean(SD)	Sex	Race/Ethnicity	Yrs as CNA Mean(SD)	Yrs at current SNF Mean(SD)
	N	-	104	109	109	110
Fair Haven	18	39.56(10.84)	Female = 16 Male = 1	AA= 16 C= 2	15.39(9.85)	6.59(6.77)
Park Manor	37	36.65(12.44)	Female = 36 Male = 1	AA = 36 C = 0 Other = 1	9.56(9.47)	6.45(6.84)
Hunter Creek	21	38.95(10.51)	Female = 21	AA = 21	14.71(8.00)	12.55(7.47)*
Forrest Manor	34	34.91(11.17)	Female = 34	AA = 29 C = 3	11.99(8.55)	4.21(4.93)
All sites	110	37.02(11.42)	Female = 107	AA = 102 C = 5 Other = 1	12.25(9.16)	6.95(6.98)

Facility demographics can be seen in Table 9. None of the facilities were able to provide us with materials related to employee training. Instead, Directors of Nursing were asked about the extent to which “end-of-life issues were discussed” in any training given to CNAs at the facility. By and large, the facilities noted that this was not a common part of the training. This was corroborated by CNAs who mentioned they had to “learn as they went” regarding caring for individuals at the end of life.

Table 10 provides a summary of scores on variable of interest discussed through the remainder of the study.

Given the unexplored nature of items assessing death exposure, bivariate correlations were used to assess the relationship between similar questions measured via open response (the

two items asking participants to estimate) and via Likert scale. When asked to report how many resident deaths they had experienced in the last six months via the open-ended item, CNAs reported an average of 5.45(SD=10.09) resident deaths. On the Likert scale item asking

Table 9.

Facility Demographics

Facility	Residents/Beds	# RNs	#LPNs	#CNAs	CNA time/resident (per day, minutes)
Fair Haven	179/197	10	50	101	157
Park Manor	141/152	20	35	95	150
Hunter Creek	68/78	6	24	45	165
Forrest Manor	170/182	32	60	122	187

Table 10.

Mean Scores of Variables of Interest

Variable (Range)	Range (Low-High)	Mean (SD)
Experiential Avoidance (AAQ-II)	1-7	3.07(1.54)
Behavioral Inhibition (BIS)	1-4	2.86(.75)
Compassion Fatigue	1-10	3.72(1.74)
Death Exposure	1-10	5.83(2.13)
Death Attitudes		
Approach Acceptance	1-7	6.09(.84)
Escape Acceptance	1-7	5.08(1.51)
Neutral Acceptance	1-7	5.70(.88)
Fear of Death	1-7	4.20(1.51)
Death Avoidance	1-7	4.35(1.53)
My Aging Preparation Scale		
Awareness	1-5	4.28(.81)
Avoidance	1-5	2.89(1.24)
Gathering Information	1-5	3.52(1.12)
Developing Preferences	1-5	4.02(.81)
Concrete Planning	1-5	3.30(1.20)
Total	1-5	3.60(.64)

participants to report “how much death” they experienced as a CNA (“resident deaths”) in the last six months, CNAs reported an average rating of 5.61(SD=3.24), which falls in the middle range of the scale. Interestingly, these two reports were not significantly correlated ($r=.17$, $p=.07$) in the sample.

When asked to report via Likert “how much death” they experienced during their lifetime in their personal lives (i.e., not counting resident deaths), CNA participants reported an average rating of 7.32(SD=2.66), which falls in the middle-high range of the scale. On the open-ended item asking individuals to estimate the number of close friends and family members lost during their “entire life,” CNA participants reported an average number of losses of 9.99(SD=6.66). These two reports were significantly correlated at a small to medium effect size of $r=.29$ ($p<.01$).

Relationship between Death Exposure and Death Attitudes

Results from the current sample of CNAs are summarized in Table 11. Overall, there does not seem to be a relationship between a CNA’s self-reported death exposure and her death-related attitudes. Nor is there any relationship between the number of years an individual has worked as a CNA and a particular pattern of attitudes (e.g., more positive or more negative). The exception seems to be a small effect size relationship between death exposure and Approach Acceptance (i.e., items viewing death as a gateway to a happier afterlife), such that a CNA reporting more death exposure also reported more Approach Acceptance of death.

Table 11.

Correlations between Death Attitudes and Death Exposure, CNA Years, Religiosity					
	Positive Death Attitudes			Negative Death Attitudes	
	Approach Acceptance	Escape Acceptance	Neutral Acceptance	Fear of Death	Death Avoidance
Death Exposure	.24*	.15	.12	-.10	-.04
CNA Years	-.08	-.07	.08	-.02	-.03
Religiosity	.29**	.16	.06	-.24*	-.11

Impact of Death Exposure on Negative Death Attitudes

Two constructs, behavioral inhibition and experiential avoidance, were considered as moderators of the impact of death exposure on negative death attitudes. Presented in Table 12 are correlations of the variables discussed in these two models. Behavioral inhibition and experiential avoidance were themselves correlated significantly ($r=.40$, $p<.001$). Interestingly, death exposure was not significantly correlated with negative death attitudes, nor either proposed moderator. However, both moderators were significantly correlated with negative death attitudes, with experiential avoidance showing a greater effect size at $r=.41$.

Table 12.

Correlations between BIS, AAQ-II, Death Exposure, and Negative Death Attitudes

	Death Exposure	Negative Death Attitudes
Behavioral Inhibition	.11	.29**
Experiential Avoidance	.04	.41***
Death Exposure	-	-.08

** $p<.01$, *** $p<.001$

Examination of BIS as moderator. A three stage hierarchical multiple regression was conducted to examine the hypothesized moderation of Behavioral Inhibition (BIS) on the relationship between death exposure and negative death attitudes. After examining assumptions, all independent variables were mean-centered to reduce issues of multicollinearity. As discussed above, in all regressions, age and religiosity were controlled in the first step given prior findings of the impact of these variables. Results are shown in Table 13. After controlling for demographic variables in step 1, death exposure and behavioral inhibition were entered in step 2, and the interaction term examining behavioral inhibition as a moderator was entered in step 3. Results of this regression revealed a small, nonsignificant amount of variance explained in the first step, $F(2,100)=2.16$, $p=.12$, suggesting a nonsignificant role of these demographic factors in

predicting negative death attitudes. In step 2, adding death exposure and behavioral inhibition to the model resulted in 13% of the variance in negative death attitudes being accounted for, $F(4,98)=3.50, p<.05$. As demonstrated in Table 13, this is the result of a significant main effect of behavioral inhibition. Finally, while the overall model remained significant in step 3, the addition of the interaction term reduced the F statistic and did not result in a significant increase in R^2 , $F(5,97)=3.09, p<.05$. Thus, we reject our hypothesis of a moderator effect of behavioral inhibition.

Table 13.

Regression Examining BIS as a moderator of Death Exposure on Negative Death Attitudes						
	Unstandardized Coefficient		Standardized Coefficient	F	R ²	ΔR ²
	B	SE	β			
Step 1				2.16	.04	.04
Religiosity	-.30	.16	-.19			
Age	-.01	.01	-.06			
Step 2				3.50*	.13	.08*
Religiosity	.28	.16	-.17			
Age	-.01	.01	-.05			
Death Exposure	-.04	.07	-.06			
Bx Inhibition	.54	.18	.29**			
Step 3				3.09*	.14	.01
Religiosity	-.26	.16	-.16			
Age	-.01	.01	-.05			
Death Exposure	-.05	.07	-.07			
Bx Inhibition	.55	.18	.30**			
Interact. Term*	.11	.09	.11			

* $p<.05$, ** $p<.01$

Examination of AAQ-II as moderator. Next, a second hierarchical regression examining moderation of experiential avoidance on the relationship between death exposure and negative death attitudes (controlling for religiosity and age) was conducted. Full results appear in

Table 14. As before, the model in Step 2 is significant owing to a main effect of experiential avoidance. The model in step 2 accounts for 20% of the variance in negative death attitudes, $F(4,97)=6.08$, $p<.001$. When the interaction term is added in step 3, the overall model stays significant, $F(5,96)=4.92$, $p<.01$. However, R^2 does not increase, and the interaction term is not itself significant.

Table 14.

Regression Examining AAQ-II as a moderator of Death Exposure on Negative Death Attitudes						
	Unstandardized		Standardized	F	R^2	ΔR^2
	Coefficient		Coefficient			
	B	SE	β			
Step 1				2.13	.04	.04
Religiosity	-.30	.16	-.19			
Age	-.01	.01	-.06			
Step 2				6.08***	.20	.16***
Religiosity	-.22	.15	-.14			
Age	-.01	.01	-.05			
Death Exposure	-.03	.07	-.05			
Exp Avoidance	.36	.08	.40***			
Step 3				4.92**	.20	.00
Religiosity	-.24	.15	-.15			
Age	-.01	.01	-.04			
Death Exposure	-.03	.07	-.04			
Exp.	.35	.09	.39***			
Avoidance						
Interact. Term*	.03	.04	.06			

** $p<.01$; *** $p<.001$

Impact of Death Attitudes on Attitudes toward Future Care Planning

Results of bivariate correlations examining the relationship between negative and positive death attitudes of CNAs and their scores on a measure of advance care planning are presented in Table 15. As can be seen, negative death attitudes, comprising fear of death and death avoidance, were not significantly related to any advance care planning subscales. However, all subscales except Avoidance were significantly related to positive death attitudes.

Positive death attitudes as moderator of exposure predicting MAPS. Next, a hierarchical multiple regression examining moderation of positive death attitudes on the relationship between death exposure and advance care planning attitudes (controlling for religiosity and age) was conducted. Full results appear in Table 16. After step 1, the model was not significant, $F(2,96)=.77$, $p=.46$. After adding death exposure and positive death attitudes in Step 2, the overall model is significant owing to two main effects, $F(4,94)=3.32$, $p<.05$.

Table 15.

Correlations between MAPS Subscales and Death Attitudes, Exposure

	Awareness	(Low)Avoidance	Gathering Info	Developing Prefs	Concrete Plan.	Total MAPS
Negative Death Attitudes	.07	-.13	.10	.04	-.15	-.04
Positive Death Attitudes	.27**	-.09	.28**	.33**	.27**	.31**
Exposure	.18	-.001	.11	.22*	.26**	.23*

** $p<.01$, *** $p<.001$

Examining the standardized coefficient values reveals that positive death attitudes are a slightly more significant predictor of advance care planning than is death exposure, but both effects significantly predict the dependent variable, $p<.05$. The model in step 2 accounts for 12% of the variance in advance care planning, which is significant. When the interaction term is added in step 3, the overall model stays significant, $F(5,93)=3.16$, $p<.05$. However, R^2 does not significantly increase, and the interaction term is not itself significant.

Table 16.

Regression Examining Positive Death Attitudes as a Moderator of Death Exposure on Advance Care Planning Attitudes

	Unstandardized Coefficient		Standardized Coefficient	F	R ²	ΔR2
	B	SE	β			
Step 1				.77	.02	.02
Religiosity	.06	.09	.07			
Age	-.01	.01	-.11			
Step 2				3.32*	.12	.11**
Religiosity	.00	.08	.00			
Age	-.01	.01	-.22			
Death Exposure	.08	.04	.24*			
Pos. Death Att.	.23	.09	.25*			
Step 3				3.16*	.15	.02
Religiosity	.01	.08	.02			
Age	-.01	.01	-.24*			
Death Exposure	-.07	.04	.22			
Pos. Death Att.	-.22	.09	.24*			
Interact. Term*	.07	.05	.15			

*p<.05

Impact of Death Exposure on Compassion Fatigue

Correlations between variables of interest are shown in Table 17. Although not part of the regression, the nonsignificant correlation between compassion fatigue and number of years worked as a CNA is shown. Although originally proposed as a mediation relationship, as shown

Table 17.

Correlations between Compassion Fatigue and Variables of Interest

	Compassion Fatigue
CNA Years	.07
Death Exposure	.24*
Negative Death Attitudes	.16
Experiential Avoidance	.59***

*p<.05, ***p<.001

in Table 17, a basic assumption of mediation is violated in that there is not a significant relationship between negative death attitudes and compassion fatigue. Thus, any mediation analysis would prove nonsignificant. However, given the relationships between variables, and the theoretical model discussed above, the relationship was examined in a moderation model.

A hierarchical multiple regression examining negative death attitudes as a moderator of the impact of death exposure on compassion fatigue, controlling for age and religiosity, was conducted. Full results are presented in Table 18. In step 2, the overall model is significant, $F(4,98)=3.14, p<.05$, with 11% of the variance explained. The model in step 2 demonstrates a significant main effect of both death exposure ($p<.05$) and negative death attitudes ($p<.05$) predicting compassion fatigue. Adding the interaction term in step 3, the overall model is still significant, $F(5,97)=3.14, p<.05$, with a nonsignificant, small gain in the F statistic, and an insignificant interaction term.

Table 18.

Regression Examining Death Attitudes as Moderator of Death Exposure on Compassion Fatigue

	Unstandardized Coefficient		Standardized Coefficient	F	R ²	ΔR ²
	B	SE	β			
Step 1				1.01	.02	.02
Religiosity	.30	.20	.14			
Age	.003	.02	.02			
Step 2				3.14*	.11	.09**
Religiosity	.29	.20	.14			
Age	-.02	.02	-.10			
Death Exposure	.23	.09	.28*			
Neg. Death Att.	.25	.12	.20*			
Step 3				3.14*	.14	.02
Religiosity	.25	.20	.12			
Age	-.01	.02	-.09			
Death Exposure	-.22	.09	.27*			
Neg. Death Att.	-.22	.12	.18			
Interact. Term*	.10	.06	.16			

* $p<.05$, ** $p<.01$

Study 3 Discussion

The goals of the current study included the following: (a) to understand the relationship between death exposure and death attitudes; (b) to understand the role of experiential avoidance and behavioral inhibition as potential moderators between death exposure and death attitudes; (c) to explore the relationship between death attitudes and preparation for future care; and (d) to explore the relationship between death attitudes and compassion fatigue.

Results indicated relatively few patterns of relationship between death exposure and death attitudes. In fact, when examining any relationship between the length of time a CNA has worked as a CNA, and her attitudes toward death, no correlations were significant. When measuring death exposure outright, still only one significant relationship emerged. Specifically, for the present sample, a CNA who is more likely to report a greater degree of death exposure is also more likely to report strong agreement with “death approach acceptance” statements. Such statements present the idea of death as a gateway to a place of eternal happiness, and include overall positive ideas about death as it relates to “heaven” and “new and glorious life.” This finding is consistent with tenants of Terror Management Theory, which suggest that increased mortality salience serves to increase defenses against death anxiety such as religious beliefs. However, in the present sample, though religiosity was significantly related to reported approach acceptance agreement ($p < .01$), religiosity was not significantly related to reported death exposure ($p > .05$).

The nondefinitive pattern of relationships between exposure to death and death-relevant attitudes discussed above is not surprising in light of previous literature which has produced as many conflicting results as concordant ones. Thus, the next phase of analyses sought to make sense of the relationships via two proposed moderators: experiential avoidance and behavioral

inhibition. Via bivariate correlational analyses, experiential avoidance was revealed to have a stronger relationship with negative death attitudes than behavioral inhibition, though both were significant. Specifically, individuals reporting stronger negative death attitudes were more likely to score higher on the measure of behavioral inhibition and the measure of experiential avoidance.

In two hierarchical multiple regression models, controlling for age and religiosity, neither variable was shown to be significant as a moderator. However, as would be predicted by the bivariate correlations, both were significant in their respective models as main effects with experiential avoidance accounting for more variance in the model than behavioral inhibition (20% vs. 13%).

One possible explanation for these findings is that CNAs who are more likely to report negative death attitudes may also have been more likely to characterize themselves as having higher experiential avoidance and/or behavioral inhibition, via the same mechanisms of an independent, negativistic reporting bias. For example, if negative death attitudes were measured physiologically (e.g., skin conductance, facial electromyography), or implicitly (e.g., Implicit Association Task) the need for self-report would be eliminated. In this case, perhaps there would be less of a reporting confound and a more significant pattern of relationships between the variables would be observed. Research has shown potential value in such “objective” measures of death attitudes, for example demonstrating that mortality cues result in distinct EEG patterns (Valentini, Koch, Nicolardi, & Aglioti, 2015).

The next phase of data analysis shifted to look at how various outcomes may be impacted by these attitudes and experiences. Specifically, two questions were addressed: what is the

impact of death exposure on advance care planning attitudes, and what is the impact of death exposure on compassion fatigue?

Bivariate correlations revealed that, overall, exposure to death was significantly related to greater global scores on the MAPS measure, indicating that an individual with greater death exposure had more developed attitudes toward advance care planning. This is consistent with the theoretical basis of the model, which posits that awareness is a necessary foundation for further action regarding advance care planning.

Correlations also demonstrated that negative death attitudes had no significant relationships with any advance care planning subscales, while positive death attitudes were significantly related with all subscales except Avoidance. Thus, results suggest that holding negative attitudes toward death does not impact advance care planning attitudes for better or worse, while holding positive attitudes toward death is likely to be related to more awareness of future advance care needs, more information gathering about future care options, more developed preferences about care options, and more concrete plans about future care.

In a hierarchical multiple regression examining positive death attitudes as a moderator of the impact of exposure on future care preparations, the overall results indicated two main effects for both death exposure ($B=.22$) and positive death attitudes ($B=.28$). However, the interaction term was not significant and we rejected the hypothesized moderation.

The final set of analyses sought to understand the impact of death exposure and negative death attitudes on compassion fatigue, given the longstanding concern with burnout and job turnover for CNAs. Correlations revealed that compassion fatigue was significantly related to death exposure, but not years as a CNA. This is an important distinction, as it helps explain why some CNAs “burnout” and some do not. Also important to note is the strong and significant

correlation between experiential avoidance and compassion fatigue. This may, for example, have implications for specific interventions aimed at decreasing burnout/fatigue (see general discussion).

The hierarchical multiple regression predicting compassion fatigue again revealed an insignificant moderation effect. However, two significant main effects in Step 2 of the regression reveal significant impacts of death exposure and negative death attitudes on compassion fatigue, even controlling for age and religiosity. The model overall accounted for 11% of the variance. Thus, CNAs reporting higher levels of death exposure and more negative death attitudes are more likely to report higher levels of compassion fatigue. Although death exposure may be difficult to decrease, certainly death attitudes are potentially malleable. Indeed, past research has shown that death attitudes are impacted through education on end-of-life related topics (Barrere, Durkin, & LaCoursiere, 2008; Hegedus, Zana, & Szabo, 2008; Pulsford, Jackson, O'Brien, Yates, & Duxbury, 2011; Wessell & Rutledge, 2005).

GENERAL DISCUSSION

Taken together, the findings from the three studies presented herein demonstrate the impact of occupational death exposure on individuals working as CNAs, and also validate the importance of CNAs as frontline, end-of-life caregivers in nursing homes. Furthermore, the findings illuminate a need for evidence-based interventions aimed at improving institutional support for CNAs as they carry the heavy weight of witness of the often difficult deaths of their residents. Though not without limitations, the present research adds to the small but growing body of research focusing on the death-related experiences of CNAs.

In Study 1, the new My Aging Preparation Scale (MAPS) was supported in a series of confirmatory factor analyses, and other analyses aimed at determining its psychometric properties. Given that the measure was previously untested, this step was necessary to confirm its appropriateness as a measure of interest in Study 3. CNAs were, unsurprisingly, demonstrated to have more developed attitudes toward future care planning than college students across all five subscales. Within the college student sample, individuals reporting more experience with personal loss (e.g., of family and friends) reported more awareness of future care needs, had gathered more information about topics, endorsed more developed preferences about future care, and had more concrete plans regarding it.

In Study 2, qualitative focus group interviews revealed that CNAs vary in their appraisals of death. Most CNAs viewed death as either negative or neutral (e.g., part of the job), with a smaller number of CNAs reporting positive views regarding death. However, in quantitative findings, CNAs reported higher mean scores on the positive death attitude scales (e.g., approach

acceptance) compared to negative death attitude scales (e.g., death avoidance). One explanation for this apparent discrepancy is demonstrated in the correlations between scales: while positive subscales were significantly and positive correlated with one another, and negative scales were significantly and positively correlated with one another, negative and positive subscales were rarely significantly related to one another in any way. The exception is a positive correlation between fear of death and neutral acceptance ($r=.20$), suggesting the more fear of death one reported, the more neutral acceptance she also reported. Thus, negative and positive death attitudes seemed to be independently functioning constructs, not mutually exclusive of one another. This finding, while interesting, is not unique to emotions regarding death. Previous research has highlighted the independence of general experiences of positive and negative affect (e.g., Watson, Clark, & Tellegen, 1988), and this finding is even stronger in Eastern cultures (Spencer-Rodgers, Peng & Wang, 2010). Moreover, such findings may suggest that decreasing negative cognitions about death does not require increases in positive cognitions about it, or vice versa. Given that each function relatively independently, interventions aimed at shifting maladaptive attitudes about death need not pitch it as “a good thing.”

Results of Study 3 contributed further, though not in anticipated ways. While neither measure of behavioral inhibition (BIS) nor experiential avoidance (AAQ-II) demonstrated successful moderation of the impact of death exposure on negative death attitudes, the regression models revealed significant main effects worth consideration. BIS and AAQ-II both proved to be significantly related to negative death attitudes, while death exposure was not, even when controlling for age and religiosity. Of the two, experiential avoidance seemed to be more robustly linked to negative death attitudes.

This finding is particularly important considering the main effects of the fourth regression demonstrating that both death exposure and negative death attitudes contribute to compassion fatigue in the current sample. Though not proposed and therefore not included in the regression, experiential avoidance was also significantly related to compassion fatigue when examined via bivariate correlation ($r=.59$). In combination, these results suggest that compassion fatigue, and perhaps to some degree job turnover, is related to individual differences in the way that CNAs view stressful aspects of their job and process resultant negative emotions. Job turnover, in addition to being costly for a facility, is particularly detrimental to resident quality of care at the end of life (Tilden, Thompason, Gajewski, & Bott, 2012), and should be of vested interest to nursing home administration to address.

Research has shown that experiential avoidance can be diminished by interventions aimed at increasing psychological flexibility. Such interventions focus on increasing mindfulness, acceptance, and ability to defuse negative emotional/cognitive states (Fledderus, Bohlmeijer, Smit, & Westerhof, 2010). In addition to being pursued among clinical samples, such organizational-level interventions have been recommended (Ganster & Rosen, 2013; Nielsen & Randall, 2013) and shown to be successful in decreasing experiential avoidance at the workplace (Bond & Hayes, 2006). Of particular relevance, such interventions have been shown to successfully reduce job-related stress and burnout in a sample of social workers (Brinkborg, Michanek, Hesser, & Berglund, 2011).

Given the present findings of the relationship between experiential avoidance and compassion fatigue, as well as the connections between negative death attitudes, experiential avoidance, and compassion fatigue, such interventions aimed at increasing psychological flexibility would be worthwhile to explore in a CNA sample. Such interventions could be

specifically formulated to discuss acceptance and cognitive defusion related to workplace stressors (e.g., staff interactions, difficult residents) and end-of-life caregiving (e.g., grief, loss, guilt). Moreover, mindfulness exercises could be adapted to fit in with realistic daily demands of the CNA position. For example, a CNA could practice mindful awareness while walking from one part of the building to another, or while helping a resident wash their hair.

In addition to negative outcomes such as job-related burnout, exposure to death as a CNA also was found to be significantly related to positive outcomes, such as more developed attitudes toward advance care planning, as measured by the MAPS. The same regression also demonstrated a main effect of positive death attitudes, such that individuals reporting more positive death attitudes were more likely to report higher scores on the MAPS. Thus it seems that, for CNAs who possess more positive death attitudes, and have more exposure to death, future care planning attitudes are more developed. This also converges with findings from the qualitative interviews, in which CNAs reported that bearing witness to the inevitability of death, and the sometimes difficult decisions that need to be made at the end of life, has changed the way in which they think about death for themselves and their loved ones. Other qualitative research has demonstrated convergent findings, suggesting that frequent end-of-life caregiving increases one's awareness of death and need to plan for the future (Dick, 2014).

Finally, though not a specific goal at the outset of this project, our findings are consonant with research and policy implications for reducing deficiencies in end-of-life care nationally. Improved engagement in advance care planning activities not only at the end of life, but across the lifespan, has been proposed as a primary avenue to address shortcomings in care for the dying in the United States (IOM, 2014). As demonstrated by the present findings in both a young, college student sample (mean age 18.6) and a middle-aged, but not selectively

chronically-ill sample (CNAs mean age 37.0), topics related to future care planning can be reliably assessed and considered. Indeed, the current results highlight the ways in which capitalizing on the experiential awareness of individuals, for example calling to mind personal loss, or in the context of work in a nursing home, might be a source of motivation to engage in thinking and planning for their own future care needs.

Previously, little attention has been paid to examining the interest or abilities of healthy, young adults to engage in planning for future care needs, or even thinking about them. Most research related to younger adults engaging in advance care planning involves individuals with chronic, life-limiting illness (Wiener et al., 2012). Even so, such research has found positive outcomes related to the ability of such young adults to participate in future care processes (e.g., Wiener et al., 2008). The present study demonstrates that healthy young individuals have the capacity to think about future care planning, and those with more personal loss may be farther along in the process than those with less personal loss. This may suggest that if future care planning can be made personal for young adults, they might be more able to engage with it in meaningful ways.

Implications of the Present Research: Intervention Opportunities and Educational Needs

Educational needs for nursing home staff have been previously acknowledged regarding a variety of issues such as pain (Jones et al., 2004), dementia (Kuske, Hanns, Luck, Angermeyer, Behrens, & Riedel-Heller, 2007), and use of certain pharmacological interventions (Stein et al., 2001). A comprehensive overview of the need for improved care for those dying in nursing homes was published over a decade ago (Wetle, Teno, Shield, Welch, & Miller, 2004) and outlined training and policy recommendations including increased education and training for staff, health care providers, and physicians, training for administration, and additional research

into interventions aimed at improving outcomes, among many other considerations (Wetle et al., 2004). One frequent and longstanding recommendation for improved nursing home staff education is on the topic of end-of-life issues and caregiving (Brazil, Brink, Kaasalainen, Kelly, & McAiney, 2012; Ersek, Kraybill, & Hansberry, 1999; Ersek, Kraybill & Hansberry, 2000; Whittaker, Kernohan, Hasson, Howerd, & McLaughlin, 2006; Zheng & Temkin-Greener, 2010). In fact, death education has been found to be necessary for the emotional work of caring for nursing home residents at the end of life (Peters et al., 2013b).

National organizations such as the Hospice and Palliative Nurses Association (HPNA) have not only acknowledged the vital role played by nursing assistants in care for those at the end of life, but have gone on to suggest improvements in care for the dying, particularly in nursing homes, cannot be achieved without education, empowerment and elevation of the role of CNA among the resident's care team (HPNA, 2013). These necessary shifts in the role, and perceived role, of CNAs can only be achieved through increased training for nursing home staff. Foremost among those who require training are the CNAs themselves. When CNAs are provided such education, outcomes include increased knowledge, awareness, and improved attitudes toward end-of-life caregiving (Wholihan & Anderson, 2013) as well as improvements in self- and supervisor-rated caregiving abilities (Ersek, Grant, & Kraybill, 2005). As can be seen in Figures 10 and 11, such educational interventions would likely include education about the dying process (e.g., symptoms), caregiving aspects relevant to end of life, information about grief relevant to families of residents and the CNA herself, and cultural factors at play.

Beyond educational needs, the present study illuminates the need for interventions that focus on validating the relationship between CNA and resident. Although restructuring every nursing home facility into a culture-change home is not a realistic possibility, small changes that

This course is organized in seven modules.

Module One
Decisions to Make

Module Two
Understanding the Grieving Process

Module Three
Support Through the Dying Process

Module Four
Cultural Issues Involving Death

Module Five
Pain Management

Module Six
Providing Care to the Dying Person

Module Seven
Processing Grief after Death

Figure 10. Example Curriculum from Commonwealth Corporation (2008) End of Life Care Training for the Certified Nursing Assistant

Content	Time	Activities
<p>Introduction to the Course</p> <ol style="list-style-type: none"> 1. Introduction of participants 2. Importance of learning about death & dying 3. Self-awareness of personal attitudes re: death. 	30 minutes	<p>Participants interview each other and introduce one another to the group.</p> <p>Story: The Horse on the Dining Room Table¹</p> <p>Follow-up discussion re: general discomfort about death, sharing relevant personal patient experiences.</p>
<p>Communicating with Patients and Families</p> <ol style="list-style-type: none"> 1. Empathetic listening 2. Open-ended questions 3. Dealing with strong emotions 4. Non-verbal communication 5. Use of presence 6. Reportable signs of distress 	90 minutes	<p>Lecture with slides: Adapted from HPNA curriculum.</p> <p>Role Playing: Empathetic listening skills.</p> <p>Video: Example of poor communication skills (<i>Little Miss Sunshine</i>: scene about death of grandfather in emergency room)</p>
<p>Pain Management</p> <ol style="list-style-type: none"> 1. Types of pain 2. Pain Assessment 3. Pain medications & side effect 4. Non-pharmacological interventions 5. Talking to families about pain 	60 minutes	<p>Lecture with slides: Adapted from HPNA curriculum</p> <p>Review of content with prizes (Individuals or teams)</p>
<p>Symptoms at the End of Life</p> <ol style="list-style-type: none"> 1. Dyspnea 2. Constipation 3. Anxiety 4. Nausea/vomiting 5. Skin breakdown 6. Confusion 7. Depression 8. Anorexia 	90 minutes	<p>Lecture with slides: Adapted from HPNA curriculum</p> <p>Small group activity: Paired groups make posters of a symptom with 2 columns:</p> <ol style="list-style-type: none"> 1) Reportable signs & symptoms 2) NA interventions. <p>Follow-up discussion: participants present their posters to group.</p>
<p>Care in the Last Hours of Life</p> <ol style="list-style-type: none"> 1. Changes in care in last hours 2. Physical signs 3. Emotional/spiritual signs 4. Supporting the family 5. Supporting one another 	90 minutes	<p>Lecture with slides: Adapted from HPNA curriculum</p> <p>Small group activity: Groups provided with human figures, and asked to draw symptoms in last hours.</p> <p>Follow-up discussion re: each symptom (both physical and emotional/spiritual).</p>

Figure 11. Example Curriculum from Wholihan & Anderson, 2013, based on recommendations from HPNA.

work toward client-centered care, empowerment of staff, and explicit investment in “care for the dying” has been shown to impact outcomes at the end of life (Forbes-Thompson & Gessert, 2005). Although some facilities aim to recognize residents following their death, such efforts often fall short. As an anecdotal example, in one local nursing home in Tuscaloosa, a memorial space is seemingly abandoned, and bears images of residents who died a number of years ago. By contrast, in many Veterans Affairs nursing homes, deceased individuals are recognized openly, their beds often draped with an American Flag, and pushed through the hallway where staff and residents alike can take part in a farewell ritual (e.g., New Hampshire Veterans Home, 2012; Losefsky, 2010).

Possible interventions should seek to acknowledge the work of CNAs as caregivers, and thank them for their emotional investment following the death of residents. Interventions could also work with facilities to allow CNAs to contribute meaningfully to memorials of deceased residents with whom they worked closely. For example, upon the death of a resident, perhaps a short memorial meeting could be held in that person’s honor. Such an event could be led by the CNA(s) closest to the resident, and/or CNAs could share with attendants a memory of the resident, meaningful story, or song/poem. Alternatively, a physical space (e.g., table in a common area) could be dedicated to memorials of recently deceased residents. CNAs could be encouraged to contribute written memories of the resident next to a photograph. In both examples, such interventions would create a physical or tangible “space” for death to be acknowledged. They would also provide opportunities and space for self-reflection and grief, which may currently only occur in fragmented bits and pieces “in the break room.” Although no such interventions could be found in the literature, a similar intervention aimed to help nurses

process the loss of their renal patients showed favorable outcomes (Tranter, Anastasiou, Bazzi, Burgess, & Josland, 2013).

Limitations

Limitations relevant to the present studies should be noted. As is always prudent, the findings should not be generalized more broadly than the current sample would allow. The sample of CNAs participating were largely African Americans, women, and all were working in the Southeastern United States. All three of these factors may intersect with attitudes regarding death, caregiving, religious beliefs, and death anxiety, among other factors not explicitly measured. Particularly relevant to note is the unique set of factors, including historical, institutional, and cultural, which influence the various outcomes related to end-of-life care for African Americans (see Sanders, Robinson, & Block, 2016 for an excellent analysis). In addition, though the variable was controlled for, religiosity is a large part of the Southern and African American culture in the Deep South, and is likely unique to this population.

Given the scope of the current project, qualitative interviews were completed in tandem with quantitative measures. Thus, a limitation to the qualitative findings is the potential influence of questions from the quantitative survey. These items may have influenced CNAs both consciously and unconsciously to relate end-of-life caregiving to a number of topics (e.g., religiosity, burn out) they may or may not have if independently interviewed.

General Conclusion

The current project adds to a growing literature of CNAs as end-of-life caregivers in skilled nursing facilities. The topic was demonstrated to be relevant and meaningful to CNA participants, but rarely a part of employee trainings. Further research should build on the present

findings, by examining potential interventions aimed to bridge the gap between CNAs role as professional caregivers, and their experience as fictive kin of residents.

At its core, this research is about the stories we tell about death and dying. Too often, and for too long, the story has been this: it is scary and bad, and should be far away, sterilized, and dealt with only when absolutely necessary. Unfortunately, this same story creeps in, and infects our views of the dying individual themselves. We have been taught, or at least allowed, to make the dying “other,” to conceptualize them as “scary and bad,” and to push them into institutions behind sterilized doors with medical warning signs. For some individuals, like CNAs, such cultural norms come to clash with their care and affection for residents in nursing homes as they near the end of life. Not everyone can be on the frontlines of providing dignity, love, and respect for those facing their last days on earth. But, for those that are there already, for CNAs and other nursing home staff, we as researchers must support efforts to help create a new culture of acceptance and space for dying in nursing homes, for the dying themselves, and for those individuals who bravely face the complex emotions inherent in such work.

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APPENDIX A
ORIGINAL PREPARATION FOR FUTURE CARE SCALE

AW1. I pay close attention to how my physical and mental capabilities are changing to assess whether I may soon need help or care.

- Not at all true of me
- Not really true of me
- Neither true nor untrue
- Somewhat true of me
- Completely true of me

AW2. I pay attention to information in the media on the risks of needing help or care in old age.

- Not at all true of me
- Not really true of me
- Neither true nor untrue
- Somewhat true of me
- Completely true of me

AW3. Talking to other people has made me think about whether I might need help or care in the future.

- Not at all true of me
- Not really true of me
- Neither true nor untrue
- Somewhat true of me
- Completely true of me

AW4. I try not to think about things like future loss of independence.

- Not at all true of me
- Not really true of me
- Neither true nor untrue
- Somewhat true of me
- Completely true of me

AV5. I don't like to think about the risk of needing help or care in the future.

- Not at all true of me
- Not really true of me
- Neither true nor untrue
- Somewhat true of me
- Completely true of me

AV6. I avoid negative topics like future dependence.

- Not at all true of me
- Not really true of me
- Neither true nor untrue
- Somewhat true of me
- Completely true of me

GI7. I have compared different options for obtaining help or care in the future.

- Not at all true of me
- Not really true of me
- Neither true nor untrue
- Somewhat true of me
- Completely true of me

GI8. I have gathered information about options for care by talking to friends and/or relatives.

- Not at all true of me
- Not really true of me
- Neither true nor untrue
- Somewhat true of me
- Completely true of me

GI9. I have gathered information about options for care by talking to health care professionals (doctors, nurses, home health care agencies)

- Not at all true of me
- Not really true of me
- Neither true nor untrue
- Somewhat true of me
- Completely true of me

DM10. I know what options for care I don't want.

- Not at all true of me
- Not really true of me
- Neither true nor untrue
- Somewhat true of me
- Completely true of me

DM11. I know my general preferences for care in the future even though I am not sure how I will get what I want.

- Not at all true of me
- Not really true of me
- Neither true nor untrue
- Somewhat true of me
- Completely true of me

DM12. If I ever need help or care, I can choose between several options that I have considered in some depth.

- Not at all true of me
- Not really true of me
- Neither true nor untrue
- Somewhat true of me
- Completely true of me

CP13. I will not consider certain types of care under any circumstance.

- Not at all true of me
- Not really true of me
- Neither true nor untrue
- Somewhat true of me
- Completely true of me

CP14. I have explained to someone close to me what my care preferences are.

- Not at all true of me
- Not really true of me
- Neither true nor untrue
- Somewhat true of me
- Completely true of me

CP15. I have written down my preferences for care.

- Not at all true of me
- Not really true of me
- Neither true nor untrue
- Somewhat true of me
- Completely true of me

APPENDIX B
MY AGING PREPARATION SCALE (MAPS)

The next questions ask about your beliefs and feelings toward preparing for your own care as you age. There is no right or wrong answer—please pick the ONE best answer for what is *true for you*.

1. I pay attention to how my body is changing to decide if I may need help or care as I age.
 - Absolutely not true of me
 - Not really true of me
 - Neither true nor untrue
 - Somewhat true of me
 - Completely true of me

2. I pay attention to how my mind is working to decide if I may need help or care as I age.
 - Absolutely not true of me
 - Not really true of me
 - Neither true nor untrue
 - Somewhat true of me
 - Completely true of me

3. I pay attention to information in the media about possible health problems as I age.
 - Absolutely not true of me
 - Not really true of me
 - Neither true nor untrue
 - Somewhat true of me
 - Completely true of me

4. When I talk with other people about age-related health problems I think about whether I may need help or care as I age.
 - Absolutely not true of me
 - Not really true of me
 - Neither true nor untrue
 - Somewhat true of me
 - Completely true of me

5. I **stay away from, or avoid, thinking about** things like not being able to take care of myself as I age (e.g., not being able to drive, not being able to feed or clothe myself).
- Absolutely not true of me
 - Not really true of me
 - Neither true nor untrue
 - Somewhat true of me
 - Completely true of me
6. I **do not like to think about** needing help or care as I age.
- Absolutely not true of me
 - Not really true of me
 - Neither true nor untrue
 - Somewhat true of me
 - Completely true of me
7. I **do not like to talk about** the possibility of needing help or care as I age.
- Absolutely not true of me
 - Not really true of me
 - Neither true nor untrue
 - Somewhat true of me
 - Completely true of me
8. I have gathered information about choices for care as I age by talking to friends and/or relatives.
- Absolutely not true of me
 - Not really true of me
 - Neither true nor untrue
 - Somewhat true of me
 - Completely true of me
9. I have gathered information about choices for care as I age by talking with doctors, nurses, or other medical staff.
- Absolutely not true of me
 - Not really true of me
 - Neither true nor untrue
 - Somewhat true of me
 - Completely true of me
10. I **understand** the information I have gathered about choices for care as I age.
- Absolutely not true of me

- Not really true of me
- Neither true nor untrue
- Somewhat true of me
- Completely true of me

11. I have compared different choices for help or care as I age.

- Absolutely not true of me
- Not really true of me
- Neither true nor untrue
- Somewhat true of me
- Completely true of me

12. Even though I am not sure how I will get it, I know what I want for care as I age.

- Absolutely not true of me
- Not really true of me
- Neither true nor untrue
- Somewhat true of me
- Completely true of me

13. I have thought carefully about my choices for care as I age.

- Absolutely not true of me
- Not really true of me
- Neither true nor untrue
- Somewhat true of me
- Completely true of me

14. I know what choices I do NOT want.

- Absolutely not true of me
- Not really true of me
- Neither true nor untrue
- Somewhat true of me
- Completely true of me

15. As of today, I know I do not want certain types of care no matter what. (e.g., using a feeding tube, going into a nursing home...)

- Absolutely not true of me
- Not really true of me
- Neither true nor untrue
- Somewhat true of me

Completely true of me

16. I have told someone close to me about the care I want.

Absolutely not true of me

Not really true of me

Neither true nor untrue

Somewhat true of me

Completely true of me

17. I believe the person(s) I told understands what I want.

Absolutely not true of me

Not really true of me

Neither true nor untrue

Somewhat true of me

Completely true of me

18. I have written down what I want for care.

Absolutely not true of me

Not really true of me

Neither true nor untrue

Somewhat true of me

Completely true of me

APPENDIX C
IRB APPROVAL CERTIFICATE FOR 101 STUDY



October 6, 2014

Morgan Eichorst
Department of Psychology
College of Arts & Sciences
Box 870348

Re: IRB#: 14-OR-345 "My Aging Preparation Survey"

Dear Ms. Eichorst:

The University of Alabama Institutional Review Board has granted approval for your proposed research.

Your application has been given expedited approval according to 45 CFR part 46. You have also been granted the requested waiver. Approval has been given under expedited review category 7 as outlined below:

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies

Your application will expire on October 5, 2015. If your research will continue beyond this date, complete the relevant portions of the IRB Renewal Application. If you wish to modify the application, complete the Modification of an Approved Protocol Form. Changes in this study cannot be initiated without IRB approval, except when necessary to eliminate apparent immediate hazards to participants. When the study closes, complete the appropriate portions of the IRB Request for Study Closure Form.

Please use reproductions of the IRB approved stamped information sheets to obtain consent from your participants.

Should you need to submit any further correspondence regarding this proposal, please include the above application number.

Good luck with your research.



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Director & Research Compliance Officer
Office of Research Compliance

APPENDIX D
IRB APPROVAL CERTIFICATE FOR CNA STUDY

Office for Research
Institutional Review Board for the
Protection of Human Subjects

THE UNIVERSITY OF
ALABAMA
R E S E A R C H

February 23, 2015

Morgan Eichorst
Department of Psychology
College of Arts & Sciences
The University of Alabama
Box 870348

Re: IRB # 14-OR-088-R1 "CNA Bereavement Study: Dissertation Pilot Study"

Dear Ms. Eichorst:

The University of Alabama Institutional Review Board has granted approval for your proposed research

Your renewal application has been given expedited approval according to 45 CFR part 46. Approval has been given under expedited review category 7 as outlined below:

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Your application will expire on February 22, 2016. If your research will continue beyond this date, complete the relevant portions of the IRB Renewal Application. If you wish to modify the application, complete the Modification of an Approved Protocol Form. Changes in this study cannot be initiated without IRB approval, except when necessary to eliminate apparent immediate hazards to participants. When the study closes, complete the appropriate portions of the IRB Study Closure Form.

Please use reproductions of the IRB approved informed consent form to obtain consent from your participants.

Should you need to submit any further correspondence regarding this proposal, please include the above application number.

Good luck with your research.



APPENDIX E FOCUS GROUP PROCEDURE

Introduction of Facilitator, Undergraduate RA, Faculty Advisor

Explain purpose of audio recording and note taking

Ground rules:

1. No right or wrong opinions
2. Everyone's opinion is valuable
3. You are the experts and we are here to learn from you
4. Everything is confidential. No one—especially your employers—will know what you said here today.

Topic we're here to discuss: Your experience working with older adults who are near death/dying

What is your experience with dying residents in this facility?

Think back to a recent resident death. What was it like for you as a CNA?

What are the policies/rules of nursing homes regarding death of residents? How do you feel about them?

Probes/Encouragement:

Would you explain further/give another example?

Has anyone had a similar/different experience?

What do others think of this question [repeat question]

Excellent. /Good. /Yes, I understand.

Conclusion statements

Over the last X minutes, we've discussed your experiences as a CNA regarding working with older adults who are near death. Of all the topics discussed, what do you think is the most important thing?

Thank you for your time!

APPENDIX F PARTICIPANT DEMOGRAPHICS

1. AGE: _____

2. GENDER

- Male
- Female

3. RACE/ETHNICITY

- African American/Black
- Caucasian/White
- Asian American
- Hispanic/Latin@
- Other: _____

4. MARITAL STATUS

- Single
- Partnered
- Married
- Divorced
- Widowed

5. EDUCATION (Mark one only)

- GED
- High School Diploma
- Trade/Vocational school
- Some college
- 2-year degree
- 4-year degree
- Advanced degree

6. How many years have you worked as a CNA total? _____

7. How many years have you worked at your current CNA position at this nursing home? _____

8. Approximately how many family members and close friends have passed away during your lifetime?
(for example, "2" or "13") _____

9. Approximately how many residents that you have worked with have died in the last 6 months?
(please take your best guess, even if you cannot remember) _____

APPENDIX G
DUKE RELIGION INDEX (DUREL)

Directions: Please answer the following questions about your religious beliefs and/ or involvement.

1. How often do you spend time in church or other religious meeting?

- A. More than once a week
- B. Once a week
- C. A few times a month
- D. A few times a year
- E. Once a year or less
- F. Never

2. How often do you spend time in private religious activities, such as prayer, meditation, or Bible study?

- A. More than once a week
- B. Once a week
- C. A few times a month
- D. A few times a year
- E. Once a year or less
- F. Never

The following section contains 3 statements about religious beliefs or experiences. Please make the extent to which each statement is true or not true for you.

3. In my life, I experience the presence of the Divine.

- A. Definitely true for me
- B. Tends to be true
- C. Unsure
- D. Tends *not* to be true
- E. Definitely *not* true

4. My religious beliefs are what really lie behind my whole approach to life.

- A. Definitely true for me
- B. Tends to be true
- C. Unsure
- D. Tends *not* to be true
- E. Definitely *not* true

5. I try hard to carry my religion over into all other dealings in life.

- A. Definitely true for me
- B. Tends to be true
- C. Unsure
- D. Tends *not* to be true
- E. Definitely *not* true

APPENDIX H
DEATH ATTITUDES PROFILE- REVISED (DAP-R)

Strongly disagree	Disagree	Moderately disagree	Undecided	Moderately agree	Agree	Strongly agree
1	2	3	4	5	6	7

1. Death is definitely a grim (ugly) experience.

1 2 3 4 5 6 7

2. The idea of my own death makes me anxious (nervous).

1 2 3 4 5 6 7

3. I avoid thoughts about death at all costs.

1 2 3 4 5 6 7

4. I believe that I will be in heaven after I die.

1 2 3 4 5 6 7

5. Death will bring an end to all my troubles.

1 2 3 4 5 6 7

6. Death should be viewed as a natural, undeniable and unavoidable event.

1 2 3 4 5 6 7

7. I am disturbed (bothered) that death is so final.

1 2 3 4 5 6 7

8. Death is an entrance to a place of ultimate satisfaction (happiness).

1 2 3 4 5 6

9. Death provides an escape from this terrible world.

1 2 3 4 5 6 7

10. Whenever the thought of death enters my mind, I try to push it away.

1 2 3 4 5 6 7

11. Death is relief from pain and suffering.

1 2 3 4 5 6 7

12. I always try not to think about death.

1 2 3 4 5 6 7

13. I believe that heaven will be a much better place than this world.

1 2 3 4 5 6 7

14. Death is a natural part of life.

1 2 3 4 5 6 7

15. Death is a union with God and eternal pleasure.

1 2 3 4 5 6 7

16. Death brings a promise of a new and glorious life.

1 2 3 4 5 6 7

17. I would neither fear death nor welcome it.

1 2 3 4 5 6 7

18. I have an intense (strong) fear of death.

1 2 3 4 5 6 7

19. I avoid thinking about death completely.

1 2 3 4 5 6 7

20. The subject of life after death troubles (worries) me greatly.

1 2 3 4 5 6 7

21. The fact that death will mean the end of everything as I know it frightens me.

1 2 3 4 5 6 7

22. I look forward to a reunion with my loved ones after I die.

1 2 3 4 5 6 7

23. I view death as a relief from earthly suffering (pain).

1 2 3 4 5 6 7

24. Death is simply a part of the process (course) of life.

1 2 3 4 5 6 7

25. I see death as a way to an eternal and blessed place.

1 2 3 4 5 6 7

26. I try to have nothing to do with the subject of death.

1 2 3 4 5 6 7

27. Death is a wonderful release of the soul.

1 2 3 4 5 6 7

28. One thing that gives me comfort in facing death is my belief in the afterlife.

1 2 3 4 5 6 7

29. I see death as a relief from the burden of this life.

1 2 3 4 5 6 7

30. Death is neither good nor bad.

1 2 3 4 5 6 7

31. I look forward to a life after death.

1 2 3 4 5 6 7

32. The uncertainty of not knowing what happens after death worries me.

1 2 3 4 5 6 7

APPENDIX I
BEHAVIORAL INHIBITION SYSTEM (BIS)

Very false for me	Somewhat false for me	Somewhat true for me	Very true for me
1	2	3	4

1. If something bad is about to happen to me, I almost always feel fear or nervousness.

1 2 3 4

2. Criticism or scolding (getting in trouble) hurts me quite a bit.

1 2 3 4

3. I feel pretty worried or upset when I think or know somebody is angry at me.

1 2 3 4

4. If I think something bad is going to happen I usually get pretty "worked up."

1 2 3 4

5. I feel worried when I think I have done poorly at something important.

1 2 3 4

6. Compared to my friends, I have very many fears.

1 2 3 4

7. I worry about making mistakes.

1 2 3 4

APPENDIX J
ACCEPTANCE AND ACTION QUESTIONNAIRE II (AAQ-II)

Never true	Very rarely true	Seldom true	Sometimes true	Frequently true	Almost always true	Always true
1	2	3	4	5	6	7

1. My painful experiences and memories make it difficult for me to live a life that I value.

1 2 3 4 5 6 7

2. I'm afraid of my feelings.

1 2 3 4 5 6 7

3. I worry that I won't be able to control my worries and feelings.

1 2 3 4 5 6 7

4. My painful memories stop me from having a fulfilling (satisfying) life.

1 2 3 4 5 6 7

5. Emotions (feelings) cause problems in my life.

1 2 3 4 5 6 7

6. It seems like most people are handling their lives better than I am.

1 2 3 4 5 6 7

7. Worries get in the way of my success.

1 2 3 4 5 6 7

APPENDIX K
COMPASSION FATIGUE SCALE-REVISED (CFS-R)

Never/ Rarely									Very often
1	2	3	4	5	6	7	8	9	10

1. I have felt trapped by my work.
2. I have thoughts that I am not succeeding in achieving my life goals.
3. I have had flashbacks connected to my residents.
4. I feel that I am a “failure” in my work.
5. I experience troubling dreams similar to those of a resident of mine.
6. I have felt a sense of hopelessness related to with working with residents.
7. I have frequently felt weak, tired or rundown as a result of my work as a CNA.
8. I have experienced intrusive (unwanted) thoughts after working with especially difficult residents.
9. I have felt depressed as a result of my work.
10. I have suddenly and unwillingly recalled a frightening experience while working with a resident.
11. I feel I am successful at separating work from my personal life.
12. I am losing sleep over a resident’s upsetting experiences.
13. I have a sense of worthlessness, discouragement, or anger/bitterness associated with my work.

**APPENDIX L
DEATH EXPOSURE**

Everyone experiences different amounts of loss and death during their lifetimes. Please use the scale below to respond to these 5 questions regarding your own experience. You may use any number from 1 (=none/not at all) to 10 (=very, very much). Circle the number that is true for you.

Not at all/ almost none									Very, very much
1	2	3	4	5	6	7	8	9	10

How much death—for example, the deaths of your family, friends, and loved ones—have you experienced:

1) During your entire life?

1 2 3 4 5 6 7 8 9 10

2) When you were a child (less than 16 years old)?

1 2 3 4 5 6 7 8 9 10

3) During the last 6 months—NOT counting deaths at work?

1 2 3 4 5 6 7 8 9 10

4) During the last 6 months as a CNA (resident deaths)?

1 2 3 4 5 6 7 8 9 10

5) While working as a CNA TOTAL?

1 2 3 4 5 6 7 8 9 10

**APPENDIX M
INSTITUTIONAL DEMOGRAPHICS**

Facility Name: _____

Administrator: _____

Location: _____

Size

of Residents:

of Beds:

Staff

of CNAs:

of RNs:

of LPNs/LVNs:

of licensed nurse staff hrs/resident/day:

of CNA hours/resident/day:

Frequency of resident deaths (last 30 days):

Employee handbook Y / N

Copy available Y / N

Formal staff training related to EOL care:

Formal staff support available: