The Meaning of Dementia-related Changes in Persons with ADRD: An Interpretive Phenomenological Exploration of African American Caregivers' Perceptions

By

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Abstract

TITLE: The Meaning of Dementia-related Changes in Persons with ADRD: An Interpretive Phenomenological Exploration of African American Caregivers' Perceptions

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Witnessing declining function in a family member with dementia can be discouraging and burdensome for caregivers. Research indicates that African American caregivers tend to manage these challenges better than White caregivers prior to the death of the care-recipients. Why this is the case is not fully understood. Little is known about the meaning these caregivers ascribe to the dementia-related changes they see in their care-recipients. For White caregivers, the changes are often equated with loss, resulting in emotions such as sadness and anger. The literature suggests that African American caregivers may perceive the changes somewhat differently.

The purpose of this interpretive phenomenological study was to gain a deeper understanding of the meanings African American family caregivers ascribe to dementia-related changes in their care-recipients. To accomplish this goal, eleven African American caregivers in the Pacific Northwest (PNW) were interviewed twice over a six week period. Analysis of the transcribed interviews was based on the hermeneutic circle—an iterative process that involves comparing themes within and across the transcripts.

Two important themes emerged from this analysis. First, despite substantial impairments from dementia, the caregivers in this study tended to *hang on* to care-recipients' remaining function and personhood. Second, despite these changes, the caregivers felt that their family members with dementia were *still here*. Interviews with the caregivers revealed that these meanings were shaped by historical, religious, and social forces.

Several implications from this study are discussed in this dissertation. First, because race concordance between African American caregivers and health care providers is the PNW is low, the findings from this study can facilitate culturally-appropriate care despite differences. Second, the themes of *hanging on* and *still here* provides insight on how these caregivers understand and utilize long term care. Third, due to the fact that African American caregivers tend to have high rates of prolonged grief disorder after the death of family members, these findings can be used to open up sensitive conversations about end-of-life concerns. Finally, theoretical implications that inform future research were also noted.

This study provides deeper insight into the African American caregiving experience. Further work that investigates these findings in the context of cross-cultural interventions has the potential to improve the caregiving experience for many caregivers across ethnic and racial boundaries.

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Glossary of Key Terms

Term	Definition	Citation
African American	A person who self-identifies as having African ancestral origins and lives in the United States, not a first generation immigrant.	Agyemang, Bhopal, Bruijnzeels, 2005
Dementia	An umbrella term that includes a variety of neurocognitive disorders that result in memory loss, personality change and physical decline. Alzheimer's disease is the most common dementia, followed by vascular dementia, mixed dementias and Lewy Body dementia.	Alzheimer's Association, 2014
Family caregiver	A family member that provides protection and assistance to another family member.	Pearlin, Mullan, Semple & Skaff, 1990
Jim Crow Laws	Instituted in 1896 with the Plessy v. Ferguson Supreme Court decision that sanctioned "separate but equal" status of African Americans. These segregationist rules resulted in methodical disenfranchisement of African Americans until they were repudiated in 1954 with the Brown vs. Board of Education decision.	Chafe, Gavins, and Korstad, 2001
She/her	These gender-specific pronouns are used in this dissertation because 66% of caregivers in the US are women.	National Alliance for Caregiving, 2009
I/we	Singular first person pronouns are used in this dissertation as fits the qualitative tradition. However, the three manuscripts use the plural first person because of the Committee's assistance with manuscript development and oversight.	

Chapter 1

Introduction

Statement of problem. In the United States, 1 in 9 older adults has Alzheimer's Disease or a Related Dementia (ADRD) (Alzheimer's Association, 2014). For African American elders, the numbers are even more concerning: they are almost twice as likely to have ADRD as Whites, (Plassman et al., 2007; Potter et al., 2009; Tang et al., 2001) experience delays in ADRD diagnosis (Clark et al., 2005) and are less likely than White persons with dementia to use medications for dementia (Zuckerman et al., 2008). The caregivers for African American persons with dementia also experience disparities, including worse physical outcomes such as higher rates of premature mortality (after controlling for cardiovascular and SES factors) (Schulz & Beach, 1999), and higher rates of complicated grief disorder after the death of their care-recipient with dementia (Goldsmith, Morrison, Vanderwerker, & Prigerson, 2008; Hebert, Dang, & Schulz, 2006). And while African American caregivers have historically limited their use of long term care for aging family members, this trend is starting to reverse (Feng, Fennell, Tyler, Clark, & Mor, 2011) suggesting increasing burden on families.

Despite these disparities, studies indicate that African American caregivers tend to have less depression and more positive appraisals of the caregiving experience than White caregivers (Lawton, Rajagopal, Brody, &

Brody, 1992; Roff et al., 2004; Sorensen & Pinquart, 2005). These studies suggest that African American caregivers may respond to the challenges of caregiving in ways that are significantly different than their White counterparts, resulting in worse physical health outcomes and more difficult post-death adjustment; but with more positive appraisals of caregiving.

Aims. To date, researchers have had limited success in understanding the reasons for these differences (Brummett, Siegler, Williams, & Dilworth-Anderson, 2012; Stevens et al., 2004). The purpose of this qualitative study was to explore these phenomena. A better understanding of these trends was achieved by exploring the meaning of care-recipient dementia-related changes (e.g., personality change and memory loss) for African American caregivers and their emotional responses to the changes.

The specific aims of this qualitative interpretive phenomenological study were to:

1. Understand the meaning African American family caregivers ascribed to the dementia-related changes in their care-recipients with ADRD.
2. Explore African American family caregivers’ emotional responses to these dementia-related changes in persons with ADRD.

Manuscripts. Three manuscripts were prepared for this dissertation to scaffold the study and report the findings (Table 1.1). First, pre-death grief was recognized as important concept for this study, but no formal definition was found in the literature. In order to better understand this concept, a manuscript was prepared that defines the concept and considers how it could be used as a middle-range theory.

Table 1.1

Manuscripts Prepared for the Dissertation

Title	Purpose	Authors	Journal	Stage of Submission
Pre-Death Grief in the Context of Dementia Caregiving: A Concept Analysis	• Defines the concept of pre-death grief. • Compares to chronic sorrow and anticipatory grief. • Proposes middle-range, situation specific theory.	Lindauer, A. & Harvath, T.A.	*Journal of Advanced Nursing*	Accepted
The Meanings Caregivers Ascribe to Dementia-Related Changes in Care-Recipients: A Meta-ethnography	• Synthesizes the qualitative literature on this topic	Lindauer, A. & Harvath, T.A.	*Research in Gerontological Nursing*	Submitted, in review
The Meaning of Dementia-Related Changes in Persons with ADRD: An Interpretive Phenomenological Exploration of African American Family Caregivers' Perceptions	• Study findings	Lindauer, A., Harvath, T.A., Berry, P., Wros, P.	*The Gerontologist*	Pending submission

Second, the literature reporting the meanings of dementia-related changes was limited, for the most part, to loss. Alternate meanings were sought and, because a synthesis of this literature was not found, a synthesis was performed and a manuscript of this work was developed. Finally, the findings of this study were collated into a manuscript which described that study process, the findings, and implications.

Background and Significance

Unpaid family caregivers provide the bulk of care for persons with dementia in the United States, with their work valued at $216 billion in 2012 alone (Alzheimer's Association, 2013). The majority of unpaid caregivers in the United States are White, but African American caregivers make up a significant proportion (13%) of the caregiver population (National Alliance for Caregiving & AARP, 2009). Though there are fewer African American caregivers, they tend to have heavier caregiving workloads. For example, African American caregivers are more likely to provide more care (assistance with three or more activities of daily living, ADLs) than White or Asian American caregivers, and are more likely than other caregivers to have household incomes less than $50,000 (Alzheimer's Association, 2013; National Alliance for Caregiving & AARP, 2009; National Alliance for Caregiving, 2009).

Despite the fact that highly stressed caregivers are more likely to place family members in long term care (Stevens et al., 2004), research indicates that the 2 million African American caregivers in US tend to limit long term care use, but this trend is beginning to reverse. The forecast for these caregivers is concerning: the population growth rate for African Americans over age 65 is over twice that of Whites (16.2 % vs. 6.7%) (Feng et al., 2011). This growth, coupled with the high prevalence of dementia in African American elders (Plassman et al., 2007), suggests ever-increasing caregiving demands for these families. Despite the dismal history of poor quality of care for African Americans in skilled nursing, it appears that skilled care is becoming a more viable option for these families (Feng et al., 2011; Smith, Feng, Fennell, Zinn, & Mor, 2007).

As the number of African American persons with dementia increases, attention needs to be directed towards preserving the physical and mental health of their family caregivers. The goal being that African American elders with dementia can age in their homes, the family values of respect and reciprocity can be supported (Sudarkasa, 1997), and long term care usage can be minimized. Of concern, studies reveal that, when compared to White caregivers, African American caregivers have worse physical health outcomes (Kiecolt-Glaser et al., 2003; Merritt, McCallum, & Fritsch, 2011) and a significantly higher risk of premature mortality (Schulz & Beach, 1999). Furthermore, African American caregivers tend to be less prepared for the death of their family member with dementia, placing them at higher risk for prolonged grief disorders (Hebert et al., 2006). Prigerson’s classic study

(1997) found that persons experiencing prolonged grief disorders are at higher risk for cancer, heart disease, and suicidal ideation.

Paradoxically, African American caregivers tend to find more satisfaction and benefits in their role than White caregivers (Haley et al., 2004; Lawton, Rajagopal, Brody, & Brody, 1992; Roff et al., 2004; Sorensen & Pinquart, 2005; Williams, 2005). They tend to feel less burdened (Skarupski, McCann, Bienias, & Evans, 2009), less anxious (Haley et al., 2004) and perceive caregiving in a more positive light (Roff et al., 2004).

To summarize, African American caregivers make up a large proportion of caregivers for persons with dementia in the US. They provide a great deal of care valued at over $28 billion in 2012 alone (Alzheimer's Association, 2013; National Alliance for Caregiving & AARP, 2009). As caregivers, their physical and mental health suffers, yet they are much less likely to use long term care services (Knight, Longmire, Dave, Kim, & David, 2007; Schulz & Beach, 1999; Stevens et al., 2004). Efforts to promote the health of these caregivers across the dementia trajectory could improve both their care-recipients and their own well-being. Effective, research-based interventions have the potential to moderate the physical and psychological toll on caregivers, their long term care service usage and post-death sequelae of prolonged grief. However, our knowledge of African Americans and dementia caregiving is still limited and therefore, our ability to develop meaningful interventions is hampered.

One area of the African American family caregiving experience that is poorly understood is how these caregivers perceive and respond to dementia-related changes in their care-recipients. Alterations in cognitive functioning, personality and physical health (Table 1.2) in family members with dementia can be difficult for many family caregivers to witness. Often these changes can be perceived as losses and a common response to these losses is grief prior to the death of the care recipients (“pre-death grief’) (Loos & Bowd, 1997; Sanders & Corley, 2003; Walker & Pomeroy, 1997). However, most of the literature which addresses loss and pre-death grief focuses on the experiences of White caregivers; knowledge of the African American family caregiver experience is limited. Only a few studies have included these caregivers in their investigations of the pre-death grief response (Diwan, Hougham, & Sachs, 2009; Lindgren, Connelly, & Gaspar, 1999; Owen, Goode, & Haley, 2001; Ross & Dagley, 2009; Sterritt & Pokorny, 1998), and there is conflicting evidence about whether pre-death grief is a common response for African American caregivers to dementia-related changes in their family members (Owen et al., 2001; Ross & Dagley, 2009).

Importantly, in studies with White participants, pre-death grief has been found to be associated with three trends that affect African American caregivers: impaired physical health (Schulz & Beach, 1999), consideration of institutionalization of care-recipients (Walker & Pomeroy, 1997), and prolonged *post*-death grief (Givens, Prigerson, Kiely, Shaffer, & Mitchell, 2011; Hebert et al., 2006). A fuller understanding of the trends may be achieved by exploring the meaning African American caregivers ascribe—not so much to *caregiving* per se, but to the dementia-related changes in their care-recipients. Several questions were considered prior to study initiation: Do African American caregivers perceive the changes, like many White caregivers, as losses? Is pre-death grief a relevant concept for African American caregivers? Does the meaning they ascribe to dementia-related changes in family members affect these caregivers' physical and psychological well-being? This study explored these questions.

Table 1.2

Common Dementia-related Changes in Persons with ADRD

Cognitive[a,b]	Personality[b,c]	Physical[a]
• Memory impairment • Disorientation to time, place, person • Difficulty completing common tasks • Difficulty learning new information • Losing items • Impaired judgment • Impaired ability to sustain conversation	• Impulsivity • Decreased extroversion, reduced expressions of love, happiness • Decreased openness • Increased stubbornness • Increased self-centeredness and egotistical behavior • Altered ability to recognize humor	• Impaired balance, gait • Incontinence (bowel and bladder) • Impaired ability to feed self

[a]Alzheimer's Association, 2013; [b]Bayles & Tomoeda, 1991; [c]Robins Wahlin & Byrne, 2011

Brief Literature Review

While other responses to dementia related-changes have been documented in the literature (Farran, Miller, Kaufman, & Davis, 1997;

Henderson & Henderson, 2002; Navab, Negarandeh, & Peyrovi, 2012), pre-death grief is by far the most commonly explored caregiver response. Pre-death grief (also referred to as anticipatory grief (Almberg, Grafstrom, & Winblad, 2000; Holley & Mast, 2010; Johansson, Sundh, Wijk, & Grimby, 2012; Ross & Dagley, 2009; Walker & Pomeroy, 1997), latent grief (Dempsey & Baago, 1998), chronic grief (Paun & Farran, 2011), partial grief (Berezin, 1970), and caregiver grief (Bull, 1998; Marwit & Meuser, 2005; Sanders & Corley, 2003) is described in the caregiving literature as the emotional, physical, and spiritual response to dementia-related changes (experienced as losses) in family members with dementia. There is a range of caregiver emotions in reaction to these losses, including sorrow, yearning, anger, panic, despair, frustration, bitterness and guilt (Kiely, Prigerson, & Mitchell, 2008; Lindgren et al., 1999; Loos & Bowd, 1997; Mayer, 2001).

Pre-death grief contributes to impaired caregiver physical health (Walker & Pomeroy, 1997), depression (Sanders & Adams, 2005) burden (Holley & Mast, 2009), loneliness (Johansson et al., 2012; Knutsen & Raholm, 2009), domestic violence (Rudd, Viney, & Preston, 1999; Sanders, Morano, & Corley, 2003) and prolonged grief after the death of a care-recipient (Ghesquiere, M., & Shear, 2011; Givens et al., 2011; Schulz, Boerner, Shear, Zhang, & Gitlin, 2006). Recently, Fowler and colleagues (2013) found that higher levels of caregiver pre-death grief were associated with impulsive and ineffectual problem-solving techniques. This is particularly concerning because persons with dementia rely on their caregivers for many decisions, from managing ADLs to consideration of placement in long term care.

In contrast, two other studies (Diwan et al., 2009; Sanders & Corley, 2003) found that some caregivers do not experience pre-death grief in response to dementia-related changes. Sanders et al. (2003) found the non-grieving caregivers in their qualitative study tended to be more grateful for the on-going presence of the person with dementia and tended to have stronger religious orientations than grieving caregivers. These authors did not discuss the races of the grievers and non-grievers.

The work of Walker and Pomeroy (1997) is often cited as foundational to understanding the effects of pre-death grief. These authors found that high levels of pre-death grief predicted almost 38% of variance in total health problems ($R^2 = .379$, $p < .01$) and led caregivers to consider long-term care placement for their care-recipients ($R^2 = .31$, $p < .001$) (n=200, race not reported) (Walker & Pomeroy, 1997). In a similar study, they found that pre-death grief explained 62% of the variance in the depression scores in the caregivers in their sample (p value not reported) (Walker & Pomeroy, 1996). In 2002, the Marwit-Meuser Caregiver Grief Index (MM-CGI) was developed, allowing for quantification of pre-death grief in family caregivers of persons with dementia (Marwit & Meuser, 2002). Using the MM-CGI, Sanders and Adams (Sanders & Adams, 2005) found that, after controlling for age, gender, general health and care-recipient problematic behaviors, pre-death grief predicted 47% (R^2=.473, p<.0005) of the variance in depression (n=122, 31% African American). Based on those findings, the authors maintained that almost half of what is typically considered depression could in fact be pre-death grief. Sub-analyses of African American data were not reported.

These studies indicate that pre-death grief is a common caregiver response to dementia-related changes in their care-recipients. It occurs across all phases of dementia (Adams & Sanders, 2004; Meuser & Marwit, 2001) and can be associated with concerning outcomes for all involved (Chan, Livingston, Jones, & Sampson, 2013). These studies used various approaches (qualitative, quantitative, mixed) with a variety of participants (spouses, adult children), Australians (Moyle, Edwards, & Clinton, 2002; Rudd et al., 1999), Swedes, (Albinsson & Strang, 2003; Johansson et al., 2012) Canadians (Dupuis, 2002; Loos & Bowd, 1997), and Israelis (Mayer, 2001), but none of the above studies specifically explored the African American family caregivers' response to dementia-related changes. While these studies suggest the concept of pre-death grief may be relevant to them, they provide limited insight into the meaning it has for African American caregivers.

Pre-death grief in African American family caregivers for persons with dementia. The literature addressing African American family caregivers' responses to dementia-related changes is sparse. The limited knowledge of this phenomenon in these caregivers is derived primarily from studies that included both African American and White caregivers. Diwan et al.'s (2009) retrospective study of 87 caregivers found that 71% of the 55 African American caregivers in the study experienced pre-death grief in response to dementia-related changes in family members. No analysis was done of the persons (29% of the total sample) who did not report pre-death grief. Ross and Dagley (2009) found that the African American caregivers in their study (40.6% of the 138 in the sample) had significantly higher (worse) pre-death grief scores on the MM-CGI Short Form (SF) (Marwit & Meuser, 2005) than the White caregivers. Of note, the reliability (α) for one of the subscales was .64. In more homogenous samples, the α's were .83 (Marwit & Meuser, 2005; Sanders, Ott, Kelber, & Noonan, 2008). This raises the question that the MM-CGI-SF measure may not have fully captured the pre-death experience of African American caregivers.

Lindgren et al.'s (1999) small quantitative study of pre-death grief included 18 African American family caregivers (54% of their sample). They found that pre-death grief was present in all stages of caregiving, across spouse and adult children caregivers, and was associated with decreased emotional health. While these authors did not analyze racial differences, the high percentage of African American caregivers in this study suggests that the findings described their pre-death grief response to dementia-related changes.

Sterritt and Pokorny's (1998) qualitative study focused on African American family caregivers' perceptions of caregiving for persons with ADRD.

The methodological approach in this qualitative study was somewhat unclear, but one of the findings was the theme of “Caregiving as an act of love” (p.133). Because of this love, the loss of the care-recipient’s psychological presence led to caregiver grief prior to care-recipient death.

Owen and colleagues’ (2001) retrospective study found that African American family caregivers were less likely than White caregivers to experience pre-death grief, but were more likely to experience the physical death of the family member with dementia as a great loss. Furthermore, African American caregivers were less prepared for the death than their White counterparts. Hebert at al.’s (2006) study found that African Americans caregivers were less likely than White caregivers to be prepared for the death of their care-recipients. Those who were less prepared for death had higher rates of prolonged grief disorder the death of care-recipients with dementia.

A secondary analysis of interviews of African American family caregivers in a qualitative study that examined how these caregivers managed the behavioral symptoms of dementia found that themes of pre-death grief emerged unsolicited. For example, one caregiver talked about her use of prayer in the face of change: “I said ‘Lord help me to understand it because I can't uhm develop this right now.’ The change in my mother you know’” (Lindauer, Harvath, & Basin, 2012, April). This statement is in accordance with studies that reveal that African American caregivers rely on religious coping strategies (Hamilton, Moore, Johnson, & Koenig, 2013;

Wallace, 2010) and place high value on family caregiving (Merritt et al., 2011; Sayegh & Knight, 2011; Sudarkasa, 1997).

Alternative meanings of dementia-related change across cultures. The above studies indicate that a common response to dementia-related changes for White caregivers is pre-death grief due to perceived losses, and this may also be true for African American caregivers. However, the literature suggests that culture, society and history shape the meaning of dementia-related changes and different cultural groups may ascribe different meanings to this phenomenon. This is consistent with the hermeneutic philosophical tradition which maintains that humans are both shaped by, and shape, their life experiences (Dreyfus & Wrathall, 2005).

There is a small body of literature that suggests that the meaning of dementia-related changes may vary across cultures. For example, Henderson & Henderson (2002) found that the members of an Oklahoman Native American family believed that their mother's hallucinations were actually revelations of communications with deceased ancestors. In this case the dementia-related changes meant the family member with dementia had new and valuable communication abilities.

In a study of Iranian caregivers for persons with dementia, investigators found that the Iranian caregivers, like ones in the US studies, experienced pre-death grief in response to dementia-related changes (Navab et al., 2012). However, the Iranian family members with dementia often recalled long-term memories of the past, causing the caregivers felt as though they were forced to live in the past with them. Having to live in the past, while at the same time recognizing the current changes in the care-recipient, caused a fair amount of anguish for the caregivers. The Iranian caregivers also felt the dementia-related changes were caused by the previous sins. The authors identified that the Iranian Muslim tradition, in which hardships are a result of past sins, influenced the meaning these caregivers ascribed to the dementia-related changes in their family members.

For African American family caregivers, some differences and some similarities to White caregivers' perceptions of dementia-related changes in persons with dementia have been noted in the literature. Farran et al. (1997) found that the African American caregivers in her study were more inclined to appreciate the on-going presence of their family member, despite the dementia-related changes. Owen et al. (2001) found that African American caregivers for persons with dementia were less likely to grieve for their family members prior to their death, but the reasons are unclear. Intriguingly, Paun (2003) found in her qualitative study (n= 5 African American and 9 White participants) that some caregivers, instead of experiencing pre-death grief in response to dementia-related change, welcomed the personality changes. In contrast, Hinton and colleagues (1999) found that, to one African American caregiver, the dementia-related changes were equated with loss and resulted in pre-death grief.

These studies fall somewhat short of addressing, in depth, the meaning of the dementia-related changes for African American caregivers, but they do suggest that culture and societal influences shape this meaning. What these studies do indicate is that the meaning that African American caregivers give to these changes is under-studied and thus a number of questions are raised. For example, do societal forces (such as racism) shape how these family caregivers perceive dementia-related changes (Rosenblatt & Wallace, 2005)? Do cultural and family values foster family bonds despite cognitive impairment (Shweder & Bourne, 1982)? Does religiosity play a role in the range of responses to these changes for African American caregivers (Wallace, 2010)? The current available literature hints that the meaning these caregivers ascribe to dementia-related changes in family members may vary from that of Whites, but this has not been explored in depth.

This study aimed to fill this important gap by investigating the meaning African American family caregivers give to dementia-related changes in the care-recipients with dementia. The findings provided a fuller understanding of what dementia related changes mean to African American family caregivers and the cultural influences that are important in understanding these caregivers' interpretations of change.

Philosophical Foundation

This study was rooted in hermeneutic phenomenology, an interpretivistic philosophical tradition loosely grounded in constructivism

(Schwandt, 2000). Hermeneutic phenomenology maintains that individuals' realities and the meanings they have are embedded in their day-to-day lives. This meaning is shaped by culture and tradition (context), but because it is intrinsic to individuals' lives, it is difficult for a person to explicitly understand or describe (Leonard, 1994; Welch, 1999). Interpretive phenomenological research involves unveiling hidden meaning and recognizing that individuals have different experiences of what is true based on their situations, their "being-in-the-world" (Heidegger, 1962, p. 174). Ontologically, hermeneutic phenomenology seeks out the *meaning* of existence and recognizes that there is not one pure truth, but multiple, subjective realities (Welch, 1999).

According to Heidegger, human beings share space and time with other human beings, and therefore, while each person is an individual, all are shaped by the context of their lives (e.g. community, culture, language) (Dreyfus & Wrathall, 2005). Shweder and Bourne (1982) maintain, similar to Heidegger, that how a person is perceived is culturally bound. For example, in the United States, the prevailing concept is that the autonomous, self-centric adult is highly valued. In socio-centric cultures, the value of a person rests in his position as a part of an interdependent network, not solely as an autonomous individual.

The value system of African American families suggests that this cultural group is more socio-centric than Whites in the U.S. Sudarkasa (1997) maintains that the cardinal value of African American families is that of respect for elders, suggesting that that physical or psychological status of an African American elder does not dictate his or her value. From the hermeneutic perspective, these cultural values could affect meaning the caregivers ascribe to dementia-related changes.

The participant-researcher relationship. The hermeneutic approach appreciates that the participants' worlds and a researcher's are entwined through time, location and culture, and therefore, a researcher cannot isolate her experience from the participants.' Hermeneutic phenomenology recognizes that there is a relationship between the participants and the researcher, and that the life experiences of all involved lend to understanding the studied phenomenon (Creswell, 2007). An important assumption in hermeneutic phenomenology is that it is impossible to separate a researcher's own personal beliefs, prejudices and knowledge from the dialogue and analysis of the interviews. Therefore, instead of attempting to "bracket" out expertise and preconceptions (as the Husserlian approach advocates) a researcher following the hermeneutic tradition recognizes and openly acknowledges any biases and knowledge (Lopez & Willis, 2004).

It was assumed that I, as the researcher, appreciated my background and beliefs as I and the participants co-constructed the meaning of their experiences (Lopez & Willis, 2004; Schwandt, 2000). In this study, my background as a nurse scientist and daughter of a person with dementia affected my and the caregivers,' understandings of their experiences and vice versa. Furthermore, I recognized that my own heritage was different from the participants and these ethnic differences between me and the participants affected our interpretations.

In summary, hermeneutic phenomenology appreciates the interconnectedness of humans and the influence of culture, time and place on one's existence in the world. This philosophical lens allowed me to appreciate the taken-for-granted lived experience of African American caregivers of persons with dementia, and, at the same time, recognized how my own background influenced interpretation and understanding of the participants' experiences.

Theoretical Considerations

As the participants and I worked together to understand the meaning of dementia-related changes, one theme that emerged for some of the caregivers was that the dementia-related changes meant that the caregivers were losing their care-recipients. This is consistent with the theory of ambiguous loss which maintains that the uncertain physical or psychological status of a loved one can cause emotional distress in those close to him or her. There are two types of ambiguous losses: physical loss with psychological presence (for example, when a loved one is sent on military missions) and psychological loss with physical presence, as is found in loved ones of persons with dementia. Ambiguous loss is thought to contribute to the pre-death grief of family caregivers for persons with dementia (Boss, Caron, & Horbal, 1988). Because some of the caregivers in this study identified the changes as losses, the theory of ambiguous loss was considered in the analysis.

The literature indicates that, for many caregivers for persons with dementia, the changes in the care-recipient are perceived as losses. As the hermeneutic tradition maintains, Boss (2007) asserts the meaning of loss is shaped by caregivers' lives, experiences, and culture. Therefore, "loss" may have a variety of meanings, both for an individual and across cultures. For example, loss may not be perceived as a negative experience or it may not be perceived as an experience resulting in pre-death grief. In addition, it is possible that some caregivers may not perceive the changes as losses.

The ambiguous loss theoretical framework was identified as a good fit for understanding the meaning African American caregivers attributed to dementia-related changes because it allowed for consideration of alternative meanings of loss. Arguably, the title of the theory "Ambiguous Loss" assumes that "loss" is part of the theory. However, Boss (2007) proposed that the experience of loss is subjective. Taken together, this indicates that, though the title of the theory may be a little too narrow, the assumptions nested in the theory allow for alternative understandings of dementia-related change. These assumptions will be reviewed here.

There are several important assumptions in ambiguous loss theory that are relevant to this study (Boss, 2007). First, ambiguous loss is a neutral term. What the loss *means* to a family varies. The literature hints that African American family caregivers may not always perceive dementia-related changes as losses (Farran et al., 1997; Paun, 2003). A second assumption is that cultural beliefs influence a person's ability to tolerate ambiguity. Heidegger (1962) would argue that the meaning of ambiguous loss is influenced by the culture in which one is situated. A third assumption in ambiguous loss theory is that the truth about an ambiguous loss is subjective. What is true about a loss is what is perceived by those experiencing the loss. Finally, the theory of ambiguous loss maintains that families can adapt to ambiguous loss and therefore, it is important to develop and employ interventions to facilitate adaptation to it. Boss (2007) recommends identifying the meaning of loss and the adaptation to loss through phenomenological research.

There is a gap in the literature about the meaning African American family caregivers for persons with dementia ascribe to dementia-related changes and there are no identified papers that discuss how (and if) these caregivers experience ambiguous loss in the face of these changes. In this study, the theory of ambiguous loss was considered in the analyses. Some cases fit well with this theory, others did not. The fit with this theory is discussed in Chapter 5.

Implications for Nursing

Culturally-relevant nursing care has the potential to improve the physical and mental health of African American family caregivers for persons with dementia. Oregon House Bill 2611 directs health care professionals to improve their understanding of the diverse needs of families across cultures (Keny-Guyer et al., 2013). This study directly answers this call by providing information needed for nurses to provide sensitive, meaningful care for African American caregivers in three important ways.

First, given that African American caregivers have more physical health problems than White caregivers (Kiecolt-Glaser et al., 2003; Schulz & Beach, 1999), nurses can address health issues in the context of the meaning that these caregivers ascribe to dementia-related changes. Anticipatory guidance and goal setting, based on these qualitative findings and tailored to African Americans, can be used to effectively address health promotion and disease management (Kearney, 2001). While only about 12% of nurses in the US are African American (U.S. Department of Labor, U.S. Bureau of Labor Statistics, 2011), nurses from all backgrounds can provide effective care through respectful listening and mutual goal-setting (Saha, Arbelaez, & Cooper, 2003).

Second, nurses can use the findings from this study to help families manage decisions about long-term care placement. In a study of time to nursing home placement, Stevens et al. (2004) found that White caregivers placed their family members much earlier in the disease process than African American caregivers. Additionally, these authors found that appraisal of the behavioral symptoms of dementia as bothersome decreased time to placement. These authors point out that it is the perception of the behaviors, not the actual behaviors, which predict placement. Nursing care that focuses on understanding the meaning of dementia-related changes can facilitate discussions with caregivers (of all ethnic backgrounds) to determine how behaviors are perceived. This information can be used for planning for long-term care, either in homes or facilities.

Finally, it has been documented that the relationship a caregiver has with the care-recipient's health care provider can affect how the caregiver copes after the death of a family member with dementia. Bass and colleagues (1991) found that support given by a health care provider *prior to* care-recipient death significantly reduces caregiver bereavement difficulties post-death. Support provided by a health care provider *after* death has less of an effect. This indicates that caregiver support prior to the death of a person with dementia can be instrumental in fostering adaptive coping post death (Bass, Bowman, & Noelker, 1991). A keen understanding of the meaning of dementia-related changes has for African American caregivers would be a solid foundation from which nurses can engage these caregivers in discussions about end-of-life.

Hebert and colleagues (2006) postulate that health care providers could help caregivers prepare for death, and thus ameliorate the negative consequences of being unprepared for the death of a family member with dementia. These investigators found that African Americans were more likely to be “not at all” (p. 687) prepared for the death of a family member with dementia. Caregivers not prepared for the death had more complicated grief symptoms over a longer period of time (Hebert et al., 2006). Advanced Practice RNs (and other PCPs) who appreciate the meaning African American caregivers give to dementia-related changes can provide important, culturally relevant support prior to the death of a family member with dementia. This could potentially reduce the risk of complicated grief in these caregivers.

Taken together, this study will provide nurses (and other health professionals) with the information needed to address three concerning issues that African American caregivers for persons with dementia face: physical health challenges, long-term care placement and post-death complicated grief. Understanding the meaning these caregivers give to dementia-related changes provides unique and important insight into their experiences. Armed with this information, nurses have the potential to provide appropriate and effective care for African American caregivers in the Pacific Northwest.

Conclusion

In summary, the meaning of dementia-related changes for African American caregivers of persons with dementia was explored in this interpretive phenomenological study. This exploration took into account the Heideggerian hermeneutic philosophical perspective which values the context of culture, society and background in the caregivers' understanding of meaning. The theory of ambiguous loss was considered as a way to understand how the caregivers interpreted the dementia-related changes. Study findings can be used in inform researchers, nurses, and caregivers of meaning of dementia-related changes for African American family caregivers of persons with dementia. In turn, this work can foster further research efforts and guide effective clinical care for both persons with dementia and their caregivers.

Chapter 2

Introduction

This chapter contains two of the three manuscripts prepared for this dissertation. A preliminary page for each manuscript is provided with the title, author information and citation. Following each preliminary page is a standalone summary of each manuscript. Due to copyright restrictions, the concept analysis manuscript is not included in this dissertation but can be found with the citation (Lindauer & A Harvath, 2014).

Concept Analysis

Table 2.1

Elements of Concept Analysis Manuscript

Title	"Pre-Death Grief in the Context of Dementia Caregiving: A Concept Analysis"
Authors' Contributions	First Author (AL): All research; manuscript preparation. Second Author (TAH): Conceptual guidance; editing
Funding	None
Citation	Lindauer, A.; Harvath, T.A.H. (2014). Pre-death grief in the context of dementia caregiving: A concept analysis. *Journal of Advanced Nursing.* doi: 10.1111/jan.12411

Concept Analysis

Purpose. The purpose of this concept analysis is to explore and define the concept pre-death grief in the context of dementia caregiving.

Review of Literature. Dementia can result in profound psychological and physical changes in afflicted persons. These changes are often perceived as losses to which caregivers respond with pre-death grief. Caregivers of PWDs describe grieving for their care-recipients long before death and often experiencing the actual care-recipient death as a relief (Jones & Martinson, 1992; Meuser & Marwit, 2001).

Even though there are multiple descriptions of pre-death grief found in the literature, a precise, consistent definition remains elusive. To examine the concept of pre-death grief in the context of dementia caregiving, a hybrid approach, using both Penrod and Hupcey's (2005) principle-based concept analysis and Chin and Kramer's (2011a) conceptualization of meaning was used.

Method. Principle-based concept analysis is a method used when a concept lacks consistent usage in the scientific literature. By examining a concept in relation to four principles (epistemological, pragmatic, linguistic, logical), theoretical components found in the scientific literature can be fused into a clear definition. Future research with the concept is therefore grounded in a meaningful, scientifically-based definition (Penrod & Hupcey, 2005) .

In contrast, Chin and Kramer (2011a) maintain that to grasp a concept, it is important to examine where and how the concept is used. This can be achieved by using their method of conceptualization of meaning, which involves identifying examples of the usage of a concept in a variety of media (including the popular literature) and then comparing how the concept is used across the identified sources. Through this process, the boundaries of a concept can be more fully appreciated.

The concept of pre-death grief in the context of dementia caregiving spans the scientific and colloquial media. Therefore, for this analysis, approaches that are consistent with contextualism (Chinn & Kramer, 2011a) and scientific inquiry (Penrod & Hupcey, 2005) were used to understand and define the concept.

Data Analysis. Forty-nine papers which met the inclusion criteria were analyzed for epistemological, pragmatic, linguistic, logical clarity (Penrod & Hupcey, 2005). Two sources from the popular media were analyzed for conceptual meaning (Davis, 2004; Eyre, 2001).

Human Subject Protection. (Not applicable to this paper)

Results, Discussion, Conclusions. The concept of pre-death grief was found to be linguistically and epistemologically immature and pragmatically and logically approaching maturity. Discussion focused on applying the concept in a middle-range, situation specific theory (Im & Meleis, 1999). As for limitations, the definition and consideration of a situation specific theory needs more exploration. Future studies would need to examine the durability of the concept as part of a larger middle-range theory. The analysis of conceptual meaning was limited and deserves further work to fully explore the concept of pre-death grief in the popular media.

Literature Synthesis

Table 2.2

Elements of the Literature Synthesis

Title	The Meanings Caregivers Ascribe to Dementia-related Changes in Care-Recipients: A Meta-Ethnography
Authors' Contributions	First Author (AL): All research; manuscript preparation. Second Author (TAH): Conceptual guidance, editing
Funding	None
Citation	Not applicable

Literature Synthesis Summary

Purpose. The purpose of this paper is to synthesize this qualitative literature in order to identify and interpret the meanings caregivers give to dementia-related changes.

Review of Literature. This full paper reviews and synthesizes the literature addressing the meanings caregivers ascribe to dementia-related changes. Please see the manuscript below.

Method. Noblit and Hare's (1988) method of meta-ethnographic synthesis was used as a guide to identify the meanings caregivers give to dementia-related changes in their care recipients.

Analysis. Noblit and Hare's (1988) approach involves exploring the current qualitative literature to identify metaphors, connections and discrepancies within the literature set. Meta-ethnographic syntheses can be understood as either reciprocal, meaning the findings in one paper mirror those of others, or as refutational, meaning the findings in one paper refute the findings in another. In a classical meta-ethnography, papers would be clearly categorized as reciprocal or refutational. However, we found that the majority of the papers in our literature set had both reciprocal and refutational findings within each of them. We therefore worked to identify the complementing and contrasting findings within each paper.

Human Subjects Protection. (Not applicable to this paper)

Results, Discussion, Conclusion. In the reciprocal synthesis, we found common metaphors suggesting that, for many family caregivers, dementia-related changes were considered problematic and distressing. These changes meant that they were losing their care recipients and their relationships. The themes in the papers we reviewed reciprocated each other by describing the similar negative meanings of loss, unwanted role change, and stigma. As discussed above, we could not find a paper that specifically refuted these findings, but we did find themes of positive attributions within most of the 31 papers we reviewed.

In our refutational analysis, we found evidence that suggests some caregivers understand dementia-related changes as positive, meaningful and important. Caregivers seized the opportunity to care and gain power. Acceptance of the changes revealed new levels of love, respect and tenderness within their changed relationships. This refutational synthesis is in contrast to our reciprocal analysis and indicates that the meanings of dementia-related changes are not always negative and may represent potential for new growth.

Discussion focused on applying the findings to Phillips and Rempusheski’s (1986) work. The meanings of dementia-related changes can be affected by how caregivers perceive the past images of their care-recipients in relation to how they see them in the present, with dementia.

How caregivers understand the changes could influence their approach to care.

Limitations included the recognitions that I may over-interpreted the findings. I also noted that it was difficult to identify papers that specifically addressed the meanings caregivers ascribed to dementia-related changes. Most of the information about the caregivers’ perceptions was embedded in papers that addressed the experience of caregiving. Due to the large number of papers that address this topic, it is possible that I overlooked papers that could have offered important insights into my work.

The Meanings Caregivers Ascribe to Dementia-related Changes in Care-Recipients: A Meta-Ethnography

Abstract

The number of persons with dementia is increasing dramatically in the US and with that growth is an increase in the number of caregivers. Caregiving is often associated with negative outcomes (burden, depression, impaired physical health). These problems persist even though much effort has been put into understanding caregiver strain. Some work has addressed the meanings caregivers ascribe to dementia-related changes and this work may provide a better understanding of the factors that influence caregiver health and well-being. Most of this work is qualitative, but no synthesis has been found of the literature addressing the meanings of dementia-related changes for caregivers. The purpose of this meta-ethnographic synthesis is to explore and interpret the literature addressing the meanings caregivers give to dementia-related changes in their care-recipients. An interpretation incorporating findings in relation to elder mistreatment is offered. Implications for nursing care and research are discussed.

Keywords: Caregivers, dementia, meaning, elder mistreatment, meta-ethnography.

The Meanings Caregivers Ascribe to Dementia-related Changes in Care-Recipients: A Meta-Ethnography

Dementia, a term used to describe multiple diseases that cause impairments in cognitive and physical functioning, affects about 5.2 million people in the United States (Alzheimer's Association, 2014). Persons with dementia often need assistance and care from family members. Caregiving is often described as difficult work that is emotionally and physically burdensome (Vitaliano, Zhang, & Scanlan, 2003; National Alliance for Caregiving & AARP, 2009) leading to several caregiver health concerns. Depression (Ornstein & Gaugler, 2012), anxiety (Mahoney, Regan, Katona, & Livingston, 2005), suicidal ideation (O'Dwyer, Moyle, & van Wyk, 2013), heart disease, hypertension, and increased risk of infection (Kiecolt-Glaser et al., 2003) have all been linked to caregiving. Despite the large amount of work done mitigate the negative effects of caregiving, caregivers continue to experience emotional and physical stress. The Alzheimer's Association's (2014) most recent report noted that 59% of caregivers reported experiencing emotional stress as a result of caregiving and 43% felt caregiving had a significant impact on their physical health.

Much of the work on the relationship between caregiving and stress has focused on caregivers' responses to the caregiving itself and the meanings they ascribe to this work. Only a small fraction of this work has explored the meaning *dementia-related changes* have for caregivers.

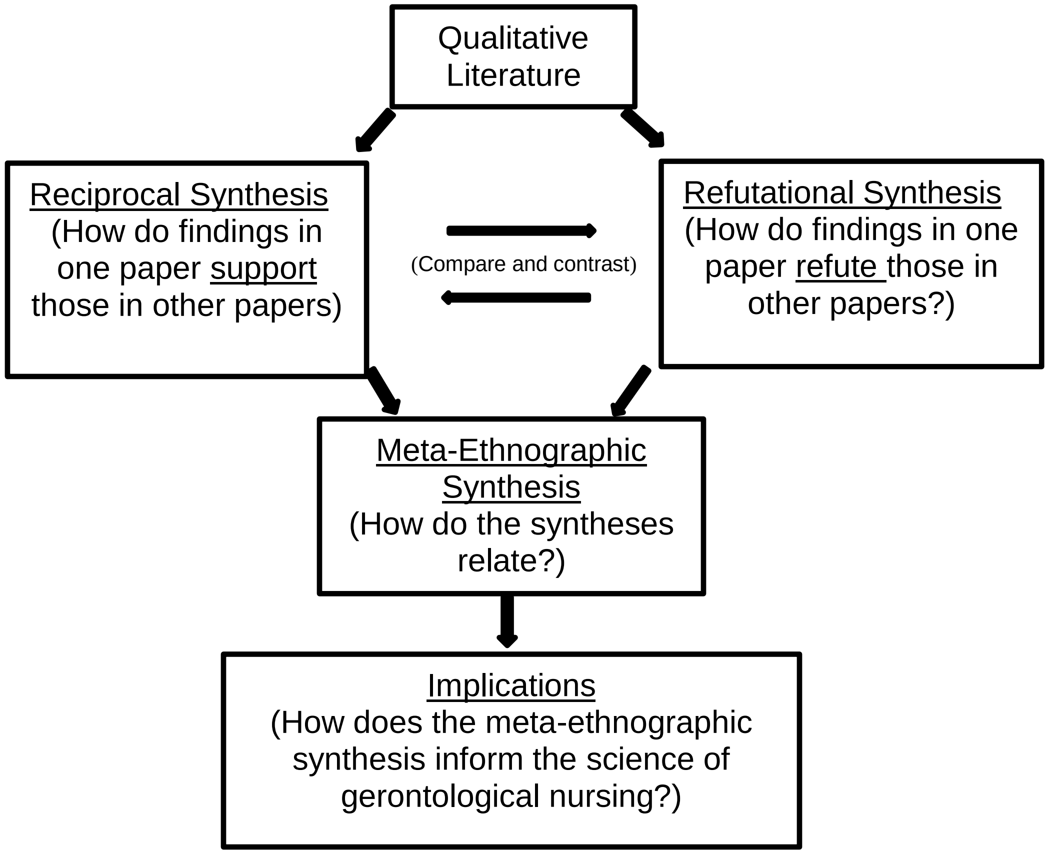
Understanding this meaning is important because it shapes how caregivers respond to, and therefore cope with, the changes they witness in their care-recipient (Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991). A deeper understanding of the meaning caregivers ascribe to dementia-related changes can contribute to the validity of measurement tools and the efficacy of interventions (DeVellis, 2012a).

Thus far, most research on the meanings of dementia–related change has been qualitative, but no syntheses of this work were identified in the current literature. Therefore, the purpose of this paper is to synthesize this qualitative literature in order to identify and interpret the meanings caregivers give to dementia-related changes.

Method

Noblit and Hare’s (1988) method of meta-ethnographic synthesis was used as a guide to identify the meanings caregivers give to dementia-related changes in their care recipients. This approach involves exploring the current qualitative literature to identify metaphors, connections and discrepancies within the literature set. Meta-ethnographic syntheses can be understood as either reciprocal, meaning the findings in one paper mirror those of others, or as refutational, meaning the findings in one paper refute the findings in another. In a classical meta-ethnography, papers would be clearly categorized as reciprocal or refutational. However, we found that the majority of the papers in our literature set had both reciprocal and refutational findings within each of them. We therefore worked to identify the complementing and contrasting findings within each paper (Figure 2.1).

Figure 2.1. Process of Meta-Ethnographic Synthesis of Papers Addressing the Meanings of Dementia-Related Changes



Adapted from *Meta-Ethnography: Synthesizing Qualitative Studies* by Noblit, G.W. and Hare, R.D. Copyright 1988 Sage Publications

Data Sources

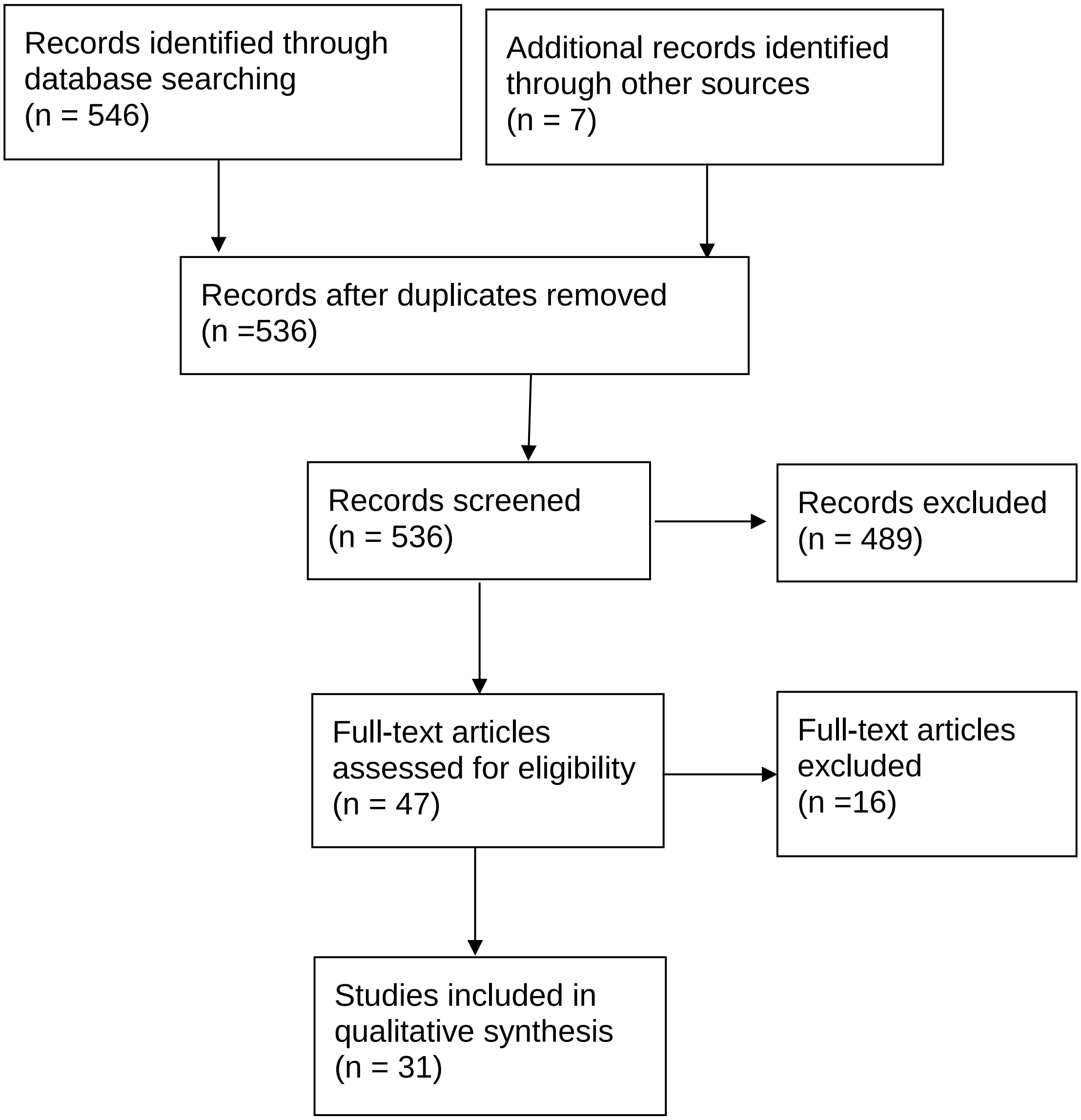
Using the PsychINFO, CINAHL, PubMed and Medline databases, the literature was searched using the terms “dementia,” “culture” “attitude,” “meaning” and “caregiving.” To broaden the searches, the terms "phenomenology," "grief," and "stigma" were added. Inclusion and exclusion criteria are listed in Table 2.3. Figure 2.2 describes the numbers of papers screened, excluded, and included. Thirty-one papers addressing the meaning family caregivers ascribe to dementia-related changes were identified. The qualitative data analysis program Dedoose (SocioCultural Research Consultants, 2014) was used to facilitate analysis. To ensure rigor, both authors reviewed the papers using Chan and Livingston's (2012) modified 8-item tool (National Institute for Health and Care Excellence, 2009). The first author rated all of the papers; the second author rated a subset. Divergence and discrepancies were discussed and resolved. The majority of the papers scored between 5 and 6, indicating fair quality.

Table 2.3

Inclusion & Exclusion Criteria for Meta-Ethnographic Synthesis

	Inclusion	Exclusion
Study type	Qualitative studies	Quantitative, mixed methods, intervention, syntheses, secondary analyses
Study focus	Caregiver responses to dementia-related changes	Caregiver responses to caregiving, retrospective
Dementia Onset	Later life	Young onset
Caregiver	Family member	Professional caregivers
Language	English language	Non-English
Year Published	2000-present	Prior to 2000
Type	Peer-reviewed journal articles	Reviews, dissertations, non-peer reviewed documents, book chapters

Figure 2.2 PRISMA Flow Chart for Identification of Literature in Meta-Ethnography



Adapted from: Preferred Reporting Items for Sytematic Reviews and Meta-Analysis: The PRISMA Statement, by D. Moher, A. Liberati, Tetzlaff,J., Altman, D.G., 2009, Journal of Clinical Epidemiology, p. 1006-1012.

Findings

Reciprocal synthesis. “Dementia” is an umbrella label for a variety of neurocognitive disorders that result in memory loss, personality change and physical decline (Alzheimer's Association, 2014). In the papers we reviewed, we found themes that indicated that these changes are perceived as losses, unwanted role changes, and stigma.

Loss. Our review of this literature set found that loss is central to the dementia caregiving experience and found across cultures. The sense of loss tended to center around personality changes in care-recipients. In a systematic review of literature on personality changes, Robins Wahlin and Byrne (2010) found that persons with dementia tend to display less warmth, engagement, and positive emotions. It was apparent that, for the caregivers in our literature set, these personality changes often were appraised as losses: a. loss of the personhood of their care-recipients, b. loss of nurturing relationships and c. loss of supportive and engaging social lives.

Loss of personhood. Caregivers described the dementia-related personality changes as loss of the care-recipient’s personhood to death, theft, or change. Often caregivers described a sense of asynchronous death; even though the care-recipient was currently living, he or she was essentially dead. Caregivers described their care-recipients as “finished” (Gillies, 2012, p. 666), “wilting” (Bursch & Butcher, 2012, p. 215) and “wither(ed)” (Mazaheri, Sunvisson, Nikbakht, Maddah, & Emami, 2011, p. 24): “Mother died five years ago, this is just a body” (Dupuis, 2002, p. 108). This asynchronous death led to pre-death grief (Lindauer & A Harvath, 2014), in which caregivers experienced a variety of emotions including sorrow and anger, and resentment for feeling emotionally abandoned by the care-recipient (Knutsen & Raholm, 2009; Navab et al., 2012; O'Shaughnessy, Lee, & Lintern, 2010).

Caregivers also described feeling as though the dementia had changed their care-recipient into a stranger (Gillies, 2012; Mayer, 2001). The dementia had altered behaviors, interests and talents to the extent that that the person with dementia was unrecognizable: “That’s not my mother any more. That’s another pleasant wee woman who looks like her who I look after” (Gillies, 2012, p.670). In some cases the care recipient exhibited bizarre behaviors that were completely out of character: “It was like living with a maniac.... We just didn’t know who this person was…” (O'Donnell, 2000, p. 55). Some caregivers described feeling as though the care-recipient had been robbed of his mind (Vellone, Sansoni, & Cohen, 2002), had been anesthetized, or had simply left: “You want to slap her silly and say, ‘Wake up, where are you?’” (Adams, 2006, p. 16).

Relationship loss. For many of the spousal caregivers in this synthesis, dementia-related changes meant relationship loss. Dementia altered care recipients to the extent that the underpinnings of normal relationships vanished, leaving caregivers feeling that they had been abandoned by their care-recipient. Emotional reciprocity disappeared as the care recipients became apathetic, withdrawn, or self-centered. Some were described as overly-affectionate, which some caregivers welcomed, yet which repulsed others. This led to confusion about intimacy: “I’ll take care of you and I'll get what you need and all that kind of stuff, but I'm not wanting to have sex with you" (Adams, 2006, p. 14). Caregivers also described feeling rejected and betrayed by their spouses (Knutsen & Raholm, 2009) because the spouse did not recognize them: "My wife calls me by the name of her first boyfriend…How can you be married to a person for 38 years and they simply reject you?" (Sanders & Corley, 2003, p. 48). For many couples, the dementia-related changes meant evaporation of reliable, nurturing relationships (Quinn, Clare, Pearce, & van Dijkhuizen, 2008; Dupuis, 2002; Walters, Oyebode, & Riley, 2010). This loss meant that caregivers had to reposition themselves within the relationship and reconcile themselves with a new, often less than ideal, state of couple hood (O'Shaughnessy et al., 2010; Paun, 2003; Perry, 2004). For a few caregivers, this loss was devastating: "She was my one and only girlfriend. I seriously thought about killing her and myself…" (Sanders et al., 2003, p. 9).

Loss of social engagement. Caregivers identified loss of their community and friends as another painful result of dementia-related changes. Friends often abandoned them and their community dwindled to only a very few devoted individuals (Daly, Mccarron, Higgins, & Mccallion, 2013; Sanders et al., 2008): "I am a lone soldier in the battleground, all others have long deserted the field" (Mayer, 2001, p. 55). Caregivers limited dining with friends (an important social event across cultures), because eating with company often revealed the behavioral symptoms of dementia or was simply messy

(Gillies, 2012; Sanders et al., 2003). The consequence of this retreat from society was isolation as care-recipients' personhood and the couples' relationships ebbed away.

Unwanted Role Change. For many caregivers in the papers we reviewed, impairments in function (toileting, eating) brought about role changes, the most common being those in which the care-recipient changed into a child-like figure (Boughtwood, Adams, Shanley, Santalucia, & Kyriazopoulos, 2011; Flores, Hinton, Barker, Franz, & Velasquez, 2009; Quinn et al., 2008). The transformation of the care-recipient from a capable adult to a seemingly dependent child was difficult for many of the caregivers. Caregivers described the care-recipient as a child, a baby, a kid. Eating behaviors and toileting issues appeared to support this perception. Caregivers noted that the care-recipient had difficulty managing food intake and often needed a bib and assistance with eating (Gillies, 2012; Perry, 2002). Caregivers felt uncomfortable when their care-recipients referred to them as parents and expressed frustration with the dwindling abilities of the care-recipient: "She is worse than a child, since surely a child grows up…" (Navab et al., 2012, p. 1082).

Stigma. Daly and colleagues (2013) identified dementia care as being situated within a social milieu, and our review found stigma to be an important caregiver concern within this social matrix. In some papers, stigma was addressed overtly (Navab, Negarandeh, Peyrovi, & Navab, 2013; Liu, Hinton, Tran, Hinton, & Barker, 2008; Vickrey et al., 2007; Werner, Goldstein, & Buchbinder, 2010), but in others, the stigma theme was more implicit (e.g., Adams, 2006). Care-recipients were stigmatized from both the community and their families as their cognitive and physical abilities deteriorated. The metaphors centered around identification of the care-recipient as incompetent, unattractive and sloppy: “God, you can’t take her no place now…she slitters all over the place and then I have to put a dish towel round her” (Gillies, 2012, p. 659). This stigma led some caregivers to avoid the care-recipient and to limit external social activities, compounding the loss of social support discussed above.

We found that the discussions of stigma figured most prominently in qualitative studies with Iranian, Vietnamese and Chinese caregivers. In these cultures, the dementia-related changes meant that family members had committed transgressions in the past and the dementia was penance for this (often unknown) sin (Navab et al., 2012; Zhan, 2004). This had internal and external stigmatizing effects. Family members felt a sense of shame (internal) and were excluded from their communities because the family was judged as lacking faith or moral integrity (external) (Navab et al., 2013; Zhan, 2004). This stigma extended to younger family members who were considered poor marriage prospects because community members felt the family was cursed (Liu et al., 2008; Mackenzie, 2006).

In our examination of this literature, we also found that persons with dementia were stigmatized because family and community members perceived them as mentally ill. Caregivers used stigmatizing metaphors such as *crazy* (Yeo, UyenTran, Hikoyeda, & Hinton, 2001; Zhan, 2004) "the same thing as schizophrenia" (Liu et al., 2008, p. 291) and "warped" (Vickrey et al., 2007, p. 242). In some societies, the care-recipient was considered contagious and therefore subtly banished from the community. This appearance of mental illness caused shame in families and motivated some families to hide their care-recipients (Mackenzie, 2006; Zhan, 2004). In Zhan's (2005) study, participants also attributed dementia-related changes to mental illness and community members identified one source of this as bad feng shui. "Some of my dad's friends suggested we relocate our house and they thought mom's 'craziness' was caused by bad feng shui" (p. 24).

Table 2.4

Metaphors Identified in the Reciprocal Synthesis

	Loss	Role Change	Stigma
Care-recipient	Dead, finished, gone wilted, withered	A child, a baby	Crazy, dirty, stupid
Relationship	Disconnection, Betrayal	Parent/child	Shame
Community	Isolation	Abandonment	Banishment

Summary, reciprocal findings. In our examination of the literature, we found common metaphors suggesting that, for many family caregivers, dementia-related changes were considered problematic and distressing.

These changes meant that they were losing their care recipients and their relationships (see Table 2.4). The themes in the papers we reviewed reciprocated each other by describing the similar negative meanings of loss, unwanted role change, and stigma. As discussed above, we could not find a paper that specifically refuted these findings, but we did find themes of positive attributions within most of the 31 papers we reviewed and these are discussed next.

Refutational synthesis. Embedded within the majority of the papers we examined were themes suggesting that the meanings of dementia-related changes were positive for some caregivers, thus implicitly refuting negative meanings discussed above (Noblit & Hare, 1988). Primarily, the dementia-related changes opened up opportunities for family caregivers. We identified three themes relating to this: a. opportunity to care, b. opportunity for power, and c. opportunity for personal growth.

Opportunity to care. Many caregivers in the papers we examined recognized that dementia-related changes meant that the care-recipient needed a caregiver. For some families, this was perceived as an opportunity to give back to the care recipient (Albinsson & Strang, 2003; Knutsen & Raholm, 2009; Mackenzie, 2006; Zhan, 2004). For example, Mazaheri (2011) found that for the Iranian caregivers in her study, the opportunity to provide care raised and supported the self-esteem of the family caregiver: “Perhaps the outsider couldn’t see how I am enjoying myself…I am looking at her and my body is filled with energy, relaxation, and satisfaction" (p. 23). Cross-cultural studies revealed that the opportunity to care opened pathways to future blessings and therefore, were sought-after experience (e.g., Mackenzie, 2006).

Opportunity for power. From another angle, the dementia-related changes provided caregivers with an opportunity to gain power in a relationship (O'Donnell, 2000; Paun, 2003; Quinn et al., 2008). This power was described as liberating, allowing the caregivers to make decisions and use resources as they saw fit, without the oversight of the care-recipient: "I'm doing what I want to do, buy what I want to buy" (O'Donnell, 2000, p. 57). Some caregivers described having increased power as "playing God," (O'Donnell, 2000, p. 57) and others described increased control: "Oh yeah, brother, I'm in control now!" (Paun, 2003, p. 303).

Henderson and Henderson's (2002) illuminating case-study revealed that, for one Native American family, the care-recipient's hallucinations allowed the family the power to communicate with dead relatives. This opportunity for the family made the care-recipient highly valuable despite her difficult and demanding behavioral symptoms of dementia.

Opportunity for personal growth. Finally, several papers noted the dementia-related changes offered opportunities for personal growth. Caregivers learned new skills (Perry, 2002; Sanders & Power, 2009) and developed new relationships with other caregivers in similar situations (Quinn et al., 2008; Vickrey et al., 2007). Caregivers recognized their own strength and valued new insight into their lives: “Something new came into my life while standing on the edge” (Knutsen & Raholm, 2009, p. 53). Other caregivers described taking pride in their caregiving skills and experiencing a sense of moral redemption (Bursch & Butcher, 2012; Mazaheri et al., 2011).

We found caregivers experienced opportunities for personal growth through acceptance. The dementia-related changes signaled to family caregivers that their care-recipients were forever altered. Therefore, caregivers aimed to recognize, appreciate, and accept what they had in the present. Caregivers described feeling an increase in tenderness, protectiveness, and respect for their care-recipients (O'Shaughnessy et al., 2010; Sanders & Power, 2009; Vellone et al., 2002). They recognized that the care-recipient had changed, accepted the changes and fully appreciated meaningful moments: “…my father…mentioned my name to me and that was better than winning the lottery” (Daly et al., 2013, p. 507).

Summary, refutational findings. In our refutational analysis, we found evidence that suggests some caregivers understand dementia-related changes as positive, meaningful and important. Caregivers seized the opportunity to care and gain power. Acceptance of the changes revealed new levels of love, respect and tenderness within their changed relationships. This refutational synthesis is in contrast to our reciprocal analysis and indicates that the meanings of dementia-related changes are not always negative and may represent potential for new growth.

The power of meta-ethnography lies in the researchers' abilities to appreciate themes within a body of literature and then to go beyond the studies by reflecting on the meaning of the corpus. Below we discuss our interpretations of our syntheses in relation to how the meaning of dementia-related changes can affect the quality of caregiving.

Discussion

The above syntheses revealed that, broadly, dementia-related changes have both negative and positive connotations for caregivers. Our interpretation is that the meanings of these changes varied among caregivers, depending on the care-recipient's premorbid personality, image and functional status. The meanings caregivers gave to the dementia-related changes were shaped by whether or not the premorbid personality was concordant or discordant with the care-recipient's current personality (L. Phillips & Rempusheski, 1986; Walters et al., 2010). We grouped our findings as (a) positive concordant, (b) negative concordant, (c) positive discordant and (d) negative discordant (Table 2.5).

Positive, concordant (Group A). These caregivers understood the care-recipients' premorbid personalities and images as essentially positive and concordant with the current image (Walters et al., 2010). In this group caregivers recognized that the dementia-related changes opened up opportunities for care and personal growth. Caregiving seemed to be motivated by love (Sterritt & Pokorny, 1998) and provided the caregivers a chance to reciprocate the care-recipient’s earlier love and care. Because of this love, the dementia-related changes meant loss, resulting in a variety of caregiver emotions, including pre-death grief. Despite feeling a sense of loss, these caregivers seemed to welcome the opportunity to provide care and did not see the changes as stigmatizing (Mazaheri et al., 2011; Walters et al., 2010).

Table 2.5

Matrix of Meanings of Dementia-related Changes

		Premorbid Personality/Image	
		Positive	Negative
Dementia-Related Changes	Concordant	Group A • Loss • Opportunity to care • Opportunity for personal growth	Group B • Opportunity for power • Unwanted role change • Stigma
	Discordant	Group C • Loss • Unwanted role change • Stigma	Group D • Opportunity for power • Opportunity for personal growth • Loss

Negative, concordant (Group B). In this group, the caregiver’s perception of the care-recipient’s pre-morbid self was negative (e.g. abusive, controlling) and was fundamentally unchanged by the dementia. In examining the literature, it appears that these caregivers also experienced opportunity, but more as an opportunity for previously-denied power. These caregivers also discussed unwanted role change, ("…it is not easy to take care of someone who never liked you"; (Sanders & Corley, 2003, p. 45) and there were subtle indications of stigma (Liu et al., 2008).

Positive, discordant (Group C). These caregivers recognized care-recipients' past images and personalities as positive (e.g., loving, supportive) and discordant with the current images (e.g., withdrawn, disinhibited). In our interpretation, the dementia-related changes meant loss, unwanted role change and stigma for these caregivers (Dupuis, 2002; Liu et al., 2008; Mayer, 2001). The change from a living, engaged person to a "living dead person" (Albinsson & Strang, 2003, p. 231), from a "best friend" (Dupuis, 2002, p. 105) to a "stranger" (Mayer, 2001, p. 55) implies that caregivers viewed the changes as undesirable. Caregivers recognized the role changes as discordant with their own and the care-recipients' past selves and used terms which implied stigma: "babyish," "childish" (Perry, 2002, p. 312). How the caregivers talked about themselves in relation to the care-recipients suggested a change to a stigmatized existence for both: "I hate being his mother and he dislikes it even more" (Bursch & Butcher, 2012, p. 212).

Negative, discordant (Group 4). In this group, caregivers perceived care-recipients' past negative images as transformed into positive ones: "He doesn't have it (a temper) now. He has a sweetness" (Perry, 2002, p. 312). With these changes, caregivers could then tap into new opportunities even though they had to adapt to unwanted role changes. For example, the dementia-related changes brought on new levels of closeness within relationships (Perry, 2004) or allowed caregivers more power within a previously unbalanced relationship (O'Donnell, 2000; Paun, 2003).

It is important to point out that the boundaries between the four groupings that we identified are not hard and fast. The very nature of personality and relationships with in the context of dementia is variable. Nonetheless, we noticed that the theme of “stigma” in Groups B and C and merits further discussion.

In Group B, the care-recipient’s pre-morbid image was considered problematic and concordant with the past image (Adams, 2006; Sanders & Corley, 2003). In Group C, the previous positive image became discordant with the current image, such as when a care-recipient’s image changed from that of a competent adult to a childish figure in need of diapers (Perry, 2002). We are most concerned with these groups because they seem to more vulnerable to elder mistreatment. Our understanding of this caregiving dynamic is based on the work of Phillips and Rempusheski (1986) who hypothesized that, when a care-recipient’s image changed from positive to negative, the image was considered “spoiled” (p. 73). When the image was considered more spoiled, caregivers tended to engage in caregiver strategies that were punitive and controlling. Phillips and Rempusheski’s (1986) model also showed that when there was positive concordance, caregivers tended to engage in more supportive, respectful treatment. Our own matrix, based on the examination of the literature, adds more detail to Phillips and Rempusheski's (1986) by demonstrating the variety of ways dementia-related changes can be perceived and the meaning caregivers give to these changes.

To summarize, we found that the meaning caregivers ascribed to dementia-related changes had both positive and negative connotations. In applying Phillips and Rempusheski's (1986) model, we see this meaning can be affected by how caregivers perceive the past images of their care-recipients in relation to how they see them in the present, with dementia. How caregivers understand the changes could influence their approach to care, with concordant negative, and discordant positive changes placing families at higher risk for elder mistreatment.

Implications for Gerontological Nurses

An important assessment component of families coping with dementia involves understanding how families came to realize their care-recipients had memory troubles. Families are often asked to describe the first signs of memory loss and the meaning of these signs. These questions offer valuable insight into the diagnostic and treatment process. Our findings from this meta-ethnography can add more depth to these interviews and alert clinicians to potentially concerning caregiving situations. For example, caregivers in the negative, concordant group may need help identifying other means of care and reassurance that their lack of desire to provide care is acceptable. Caregivers in the positive, discordant group will most likely need guidance on pre-death grief and the normalcy of this process. Both groups need to be encouraged to tap into available resources because the combination of cognitive impairment, social isolation and disharmony within families are all known risk factors for elder abuse (Johannesen & LoGiudice, 2013).

This meta-ethnography also presents opportunities for further research. We examined Phillips and Rempusheski's (1986) model of quality caregiving in relation to our synthesis, but more work is needed to explore the relationship between the meanings of dementia-related changes and quality caregiving. For example, many of the papers we examined revealed generally positive relationships between caregivers and care-recipients. Qualitative studies that examine strained relationships prior to dementing illness would add depth to our understanding of caregiving and elder mistreatment.

Limitations

We identified two main limitations. First, it is possible that we over-interpreted the relationship between the meaning caregivers ascribe to dementia-related changes and quality of caregiving for their recipients. However, Cooper et al. (2008) reported that nearly 25% of dependent persons are exposed to significant psychological abuse. This coupled with the high prevalence of physical abuse in a rapidly growing dementia population motivates us to pay attention to family safety and poor caregiving quality.

Second, despite our efforts, it was difficult to identify papers that specifically addressed the meanings caregivers ascribed to dementia-related changes. We found that most of the information about the caregivers' perceptions was embedded in papers that addressed the experience of caregiving. Due to the large number of papers that address this topic, it is possible that we overlooked papers that could have offered important insights to our work. Additionally, Bondas and Hall (2012) recommend limiting meta-synthesis to 10 to 12 papers. We aimed to stay open to the many interpretations of dementia-related change and thus we were unable to limit our literature set to a dozen.

Conclusion

We found in this meta-ethnographic synthesis that dementia-related changes can mean loss, stigma, and opportunity for caregivers. A pattern emerged in which we recognized that how a caregiver perceives a care-recipient's premorbid personality influenced this meaning. This recognition was shaped by previous nurse researchers who shared both their study findings and how they conceptualized this information. (L. Phillips & Rempusheski, 1986; Walters et al., 2010). Similarly, we hope our synthesis promotes ongoing conversation about the challenges families living with dementia face.

Noblit and Hare (1988) argue that metaethnographic syntheses can be understood as “a way of talking about our work and comparing it to the work of others” (p. 13). We agree with this assessment and recognize that our interpretation of this meta-ethnographic synthesis is not a positivistic statement of the truth, but rather a means of stimulating conversation and thought. Future research on the meaning of dementia-related changes and how these changes influence quality of caregiving could support or refute our findings. What matters is the exploratory process, and thus, ongoing efforts to support families, continues.

Chapter 3

Introduction

The purpose of this interpretive phenomenological study was to twofold: First, to gain an understanding of the meaning African American caregivers in the Pacific Northwest (PNW) ascribed to the dementia-related changes in their family members with dementia. The second aim was to explore African American family caregivers' emotional responses to these dementia-related changes in family members with dementia. This chapter discusses the method used to conduct this study.

Study Method

Interpretive phenomenology as described by Benner and her colleagues (Benner, 1994; Crist & Tanner, 2003) was the method used to explore and interpret the lived experience of African American family caregivers of persons with dementia. This approach respects the hermeneutic orientation that the caregivers' experiences are embedded in their everyday lives and shaped by their culture. Because they are situated in their own lives, the meanings caregivers ascribe to dementia-related changes and their reactions to these changes may be taken for granted. The goal in this study was to uncover the tacit meaning of dementia-related changes in care-recipients which is embodied in the caregivers' day-to-day lives (Benner, 1994).

Rationale for study method. Interpretive phenomenology is seated in the hermeneutic philosophical tradition. While this tradition is complex, there are four main reasons why this method was a good fit for this study; these reasons are discussed below.

First, the orientation to the knowledge being sought was ontological. That is I sought out the *meaning* of dementia-related changes, not what the dementia-related changes *were* (epistemological approaches) (Koch, 1995). Heidegger explains, "…meaning is that wherein the understandability of something maintains itself—even that of something that does not come into view explicitly…(Heidegger, 1962, p. 370). In other words, in order to grasp the meaning of the dementia-related changes, I needed to investigate what changes the caregivers perceived and how they *understood* these changes.

This method of searching for meaning varies from descriptive phenomenology (epistemological approach), in that the investigator seeks out what the dementia-related changes are. For example, an investigator might discover that an African American caregiver describes her care-recipient with dementia as being emotionally withdrawn. Using an ontological approach an investigator would instead focus on the meaning of the withdrawal. For example, the withdrawal might mean that caregiver feels as though she is losing the care-recipient "inch by inch," (Jones & Martinson, 1992, p. 175) leading to a sense of grief prior to the death of the loved one with dementia (*pre-death grief*) (Lindauer & A Harvath, 2014). The ontological approach recognizes that the meaning of a phenomenon drives the responses to it. Interpretive phenomenology is the method of choice when the goal is to understand meaning.

Second, time is an important construct in interpretive phenomenology in that time is valued as force that shapes how humans live in and interpret their worlds (McConnell-Henry, Chapman, & Francis, 2009; Sandelowski, 1999). As indicated in the Glossary, dementia, for the most part, is a progressive neurocognitive condition, meaning that persons with dementia *change over time*. The past, present, and future all are palpably experienced in persons with dementia and their caregivers, but not always in a linear fashion. For example, Navab and colleagues (2012) found that caregivers of persons with dementia felt as though they lived in a “whirlpool of time,” in which care-recipient memories pulled the caregivers back to a time when care-recipients had more cognitive function, but the care-recipients’ changing abilities emphasized present losses. In the current study, I sought to understand the caregivers’ perceptions of care-recipient changes (or lack thereof) over time. Recognizing that time and dementia-related changes may not be a linear process for these families allowed the participants and me to appreciate the complexity of their experiences and the multiple meanings they ascribed to these changes.

Appreciating *time* in this study also allowed me to grasp the concept and influences of time more broadly. Heidegger felt that the human experience was defined by time, past, present and future. In this study, I found the history (past time) of slavery was not only understood as an important historical event for these caregivers, but actually shaped how and why they cared for their elders (current time). For some, this history was taken-for-granted and not always explicit. Others described the history of slavery having a direct impact on current caregiving practices. For all the caregivers, it appears that their caregiving was situated in this history.

The third reason interpretive phenomenology was a good fit for this study is that one of its foundational concepts is that truth has multiple, subjective meanings that are situated in the context of participants' lives (McConnell-Henry et al., 2009). This idea that the multiple ways of experiencing a phenomenon can all be true respects the experiences of the caregivers in this study. The literature indicates that the meaning of dementia-related changes can vary for caregivers and this meaning is shaped by relationships, culture, and society (Boss et al., 1988; Rudd et al., 1999). Interpretive phenomenology recognizes all these responses as true and does not force a distillation of multiple experiences in to one truth.

Finally, the interpretive phenomenological approach assumes that the human experience is embodied, meaning our perceptions, emotions, and actions are experienced as a singular unit. A person lives in the world not as a dichotomous mind-body unit, but as a full person who is shaped by culture, society, and time (Leonard, 1994). Embodied beings, according to

Heidegger, have three modes of involvement with the world: ready-to-hand (or smooth, unconscious behaviors and actions), present-at-hand (thoughtful, reflective actions) and unready-to-hand (concerted effort, typically when there is a system or communication breakdown) (Plager, 1994). For example, an experienced caregiver, using her full self (mind and body together) would prepare a meal for a care-recipient in a ready-to-hand fashion. Her care-recipient's food preferences, eating abilities, meal timing, location, and the family's history of meal preparation and consumption would be unobtrusive background information that would influence the caregiver's task, but would not be consciously considered. However, if the care-recipient developed constipation, the caregiver might need to consciously consider foods that may help, and her work would be considered present-at-hand. Lastly, if the care-recipient began choking on food, the caregiver would likely be in a new, un-ready-to hand situation and would be faced with many decisions, some of which may be stressful. For example, could the care-recipient continue eating a regular diet?

Interpretive phenomenological research attempts to collect information about the ready-to-hand state. Here, the participants are absorbed in their daily lives and the meaning of their experience is not actively considered. Because meaning is not always consciously considered, it is not monitored or edited by the caregiver, it is authentic. My task was to access the ready-to-hand experience through interviews and observations and to identify the meaning embedded in the caregivers' experiences (Benner, 1994; Plager, 1994).

To summarize, there are four reasons that the interpretive phenomenological approach was appropriate for this study: it has an ontological orientation which recognizes time and context as integral to the human experience. Truth is appreciated as subjective and is experienced through the full person. Two other methods were considered for this study, descriptive phenomenology and a quantitative approach. However, these methods aim to find a common truth that is objective and independent of context (Lopez & Willis, 2004). These approaches would not have respected the multiple meanings caregivers ascribed to dementia related changes and thus would not have met the goals of this study.

Study Design

Setting. Qualitative research takes place in the natural setting, not in a lab or office (Creswell, 2009). This study was conducted in the community in private locations chosen by the participants. Most of the interviews took place in the caregivers' homes, one in a university library. The main requirement of the interview setting was that it was private and comfortable, so that the caregivers felt free to divulge information about their experiences. Each caregiver was interviewed twice. A subsample of caregivers was observed interacting with their care-recipients. These observations were done in the care-recipients' homes. Four caregivers took part in the observation session.

Participants. The target population was African American family caregivers for persons with mild, moderate, or severe dementia (see Glossary) living within 50 miles of Portland, OR. Based on US Census and Alzheimer's Association data, the total number of African American persons with ADRD (and thus caregivers) in Multnomah County is about 900 (Alzheimer's Association, 2013; U.S. Census Bureau, 2013). However, the qualitative nature of this study depended not on a large volume of participants, but rather on a deep understanding of the issue at hand (Miles & Huberman, 1994). Therefore, 11 African American caregivers were recruited for this study. The care-recipients were related or fictive kin; (Stack, 1974). Fictive kin are members within a family who are not related by blood or marriage (Stewart, 2007). Table 3.1 lists the inclusion/exclusion criteria.

Table 3.1

Inclusion and Exclusion Criteria for Study

Inclusion	Exclusion
• African American • Family caregiver for person with dementia • Provides 4 hours or more of care per month • Caregiver for at least one month • Over age 18 • Speaks English • Lives within 50 miles of Lead Investigator	• First generation immigrant from outside US • Care-recipient is not an identified family member

There are two areas inclusion criteria that need clarification. First, what criteria were used to designate a family member as a caregiver, and second, how was the diagnosis of dementia verified?

Family caregivers provide a wide range of care, from assistance with Independent Activities of Daily Living (IADLs) to full physical care to oversight of other care providers (such as long term care staff) (Table 3.2). There is also a wide range of hours that caregivers provide care. The literature documents that family caregivers for persons with dementia provide care for brief, intermittent periods (such as visiting a care-recipient in a long-term care facility) (Dupuis, 2002) to providing extensive care at home (Chenoweth & Spencer, 1986).

Table 3.2

Examples of Care Provided by Family Caregivers for Persons with Dementia

IADLs[a]	ADLs[b]	Communication
Grocery Shopping	Physical care	Long-term planning
Medication Administration	Continence management	Care supervision of PWD in long term care
Financial and legal help	Supervision of person with dementia	Communication with other family members
Transportation	Household chores	End-of-life attendance
Emotional support	Emotional support	Emotional support

[a]Independent Activities of Daily Living; [b]Activities of Daily Living
Note. Adapted from “Caregiving in the U.S.” by National Alliance for Caregiving and the AARP, 2009 and from “2013 Alzheimer’s Disease Facts and Figures,” Alzheimer’s Association, 2013.

Due to the wide range of hours of care, the inclusion criteria for hours of care provided by caregivers in this study were minimal (4 hours/month or more). Caregivers for persons with dementia respond to dementia-related changes in their care-recipient despite their living arrangements (Givens et al., 2011; Jones & Martinson, 1992). Therefore, the care-recipient and caregiver did not need to live together to be in this study.

Second, the dementia diagnosis in the care-recipient was confirmed with potential participant screening using the Alzheimer's Association's Criteria for all-cause dementia (Alzheimer's Disease Dementia Workgroup, 2010). These criteria included cognitive and behavior changes which: (a) interfere with work or social activities, (b) represent a decline from previous functioning, and (c) are not explained by delirium or major psychotic disorder. Additional characteristics, as described by persons with dementia or family members, included impaired ability to retain new information, impaired reasoning, impaired visual-spatial and language skills and personality change. Potential participants who had good evidence that their family member met these criteria were included in the study.

Participants were recruited using purposive, snowball sampling in order to identify information-rich cases in a community where there may be a limited number of participants (Patton, 2002). Recruitment and data collection occurred concurrently. The Oregon Health & Science University (OHSU) Layton Center and organizations such as The Marie Smith Center, and Vancouver Avenue First Baptist Church assisted me, the lead investigator, in identifying potential participants. These organizations provide care services to African American persons with dementia such as health care, day care, meal services and spiritual support. Prior to study initiation, these organizations communicated their willingness to assist with recruitment by placing flyers in their buildings with the study information and my contact information (see Appendix A). Flyers were also be posted in the community in places that provided services to potential participants, such as hair salons and barber shops that cater specifically to the African American community (see Appendix B).

Recruitment was facilitated by assistance from two community advisors: one African American nurse and one African American businesswoman. These advisors referred potential participants to the study via word of mouth. Importantly, they provided character references for potential participants who did not know me. Please see Appendix C for community advisors' roles and responsibilities.

Once potential participants were identified, I contacted them by phone, described the study, and ascertained if they were interested in eligibility screening. If they met study criteria, the study, and what it involved (e.g., two interviews and an optional observational experience), were explained. If they were interested, appointments were made to go over the study again, review the consent form, and start the interviews (please see Appendix D for Screening Process Form).

At the first visit, the consent form was given to the caregivers. Any questions or concerns were addressed. The caregiver was asked to sign two copies of the same consent form (Appendix E). One copy was retained by the investigator and one for the caregiver (participant).

For families who agreed to participate in the optional observational aspect of the study (see below for further description) consent from the care-recipient was also obtained (see “Consent and Authorization – Decisionally Impaired Person”, Appendix E). The consent process for the person with dementia was done prior to the observation session. Some of the persons with dementia did not have the cognitive function to understand the study or agree to consent. In this case, I asked the caregiver if he or she was the Legally Authorized Representative (LAR) for the person with dementia. If so, I asked this person to consent for the person with dementia, following the standards set forth in the OHSU Guidelines for Decisionally Impaired Adults. The care-recipient (or ARR) was asked to sign two identical consent forms. One copy was given to the care-recipient and one will be retained by the investigator. OHSU policy states the ARR’s name, contact information, phone number and date of designation of ARR be documented. This information was documented on the care-recipient’s consent form and kept in a locked file. The ARR’s information is only on the care-recipient’s consent form and is not stored in the study electronic database. Even when the representative signed the consent, I was observant for signs that the person with dementia was uncomfortable with my presence. Dissent would have been honored if the care-recipient stated verbally that she did want to participate, displayed a negative emotional response (e.g., sadness or fearfulness) or demonstrated behaviors that indicated dissent (e.g., agitation, withdrawal) (Black, Rabins, Sugarman, & Karlawish, 2010) However, all of the participants appeared at ease during the interview sessions.

Data Collection Procedures

In this phenomenological study, 11 caregivers were interviewed twice in private settings: once at the time of study enrollment and then again approximately 2-6 weeks later. A subsample of the participants (N=4) was observed caring for their family member with dementia between the two interviews. Minimal demographic data was collected in order to describe the sample (see Appendix F).

Interviews. The goal of the interviews was to elicit the meaning participants ascribed to the dementia-related changes in their family members with dementia (See Appendix G, Interview Guide). Because the meaning of these changes may have been taken for granted, I thought it might be difficult for caregivers to specifically articulate their experiences. Benner (1994) advised using story-telling to tap into the caregivers' authentic experiences (as opposed to attempting to answer my specific questions with sociallyacceptable answers). Together, with the use of storytelling (narratives), the participants and I worked to uncover the meaning of dementia-related changes for these caregivers.

The use of narratives allowed for the meaning of the dementia-related changes to emerge within a culturally acceptable mode of exchange: telling a story. Story telling is a respectful interactive process which has significant value within the African-American culture (Wallace, 2010). Therefore, the interviews began by asking caregivers to tell me a story, for example: "Please tell me a story about what your mother was like when you were growing up." A series of prompts were developed and used as needed to elicit how the caregiver perceived dementia-related changes and the influence culture had on these perceptions (Rubin & Rubin, 2005). The emergent nature of design of this study allowed for the evolution and alteration of questions as lines of inquiry were identified in the interviews (Benner, 1994; Crist & Tanner, 2003).

For each caregiver, a second interview took place 2 to 6 weeks after the first one, and after the observation session, to assure understanding between the participant's contributions and my interpretations (see below for descriptions of observation sessions). Prior to the second interview, the transcript of the first interview was read and early analysis completed. In the second interview, key themes from the first interview and observation (if applicable) were reviewed and clarified. Questions that arose between the first interview and observation (either for the participant or me) were addressed.

The interviews took between 35 to 90 minutes and were digitally recorded. The participant was advised that either she or I may end the interviews prematurely if the caregiver expresses signs of fatigue or upset.

Observations. In interpretive phenomenology, an investigator attempts to understand the ready-to-hand (taken-for-granted) experiences of the participants (Plager, 1994). In this study, non-participant, unstructured observation was used to facilitate understanding of the participants' lived experiences through witnessing their caregiving in the context of their daily lives. Dimensions of the caregiver/care-recipient relationships not identified in interviews were revealed through observing families in the privacy of their home (Briggs, Askham, Norman, & Redfern, 2003).

When a caregiver and care-recipient pair agreed to participate in the observation sub-sample, I met them in the care-recipient's home and observed an activity (See Appendix H, Observation Guide). I asked the caregiver to suggest an activity that revealed the care-recipient's dementia-related changes (e.g., getting dressed).

Each caregiver/care-recipient pair that agreed to the observation session was observed only once, for about one hour. For these families it appeared difficult to have me in their home without engaging me. Therefore for all of the observations the main task was "entertaining a stranger" (me). In all observation sessions, the participants were advised that the purpose of the observation was not to critique her skills or the care-recipient’s abilities, but rather to respectfully understand their experience.

During observation, the interactions, dialogue, cues, tone, affect, and non-verbal exchanges between the caregiver and recipient were noted as the dyad engaged in a familiar task. No audio or video recordings occurred during observation; field notes were taken (Creswell, 2009). After the observation session, and after I had left the home, I dictated my observations. This dictation was transcribed and incorporated into the analyses.

The observation sessions provided clues to important lines of inquiry that were addressed at the second interview, thereby adding depth and insight to the interview findings. Additionally, Patton (2002b) maintains that a meaningful description of a participant’s situation provides the scaffolding needed for thoughtful and pertinent interpretations. Therefore, information from the observations was used to fill out and add detail to the descriptions of the caregiver’s situated lives.

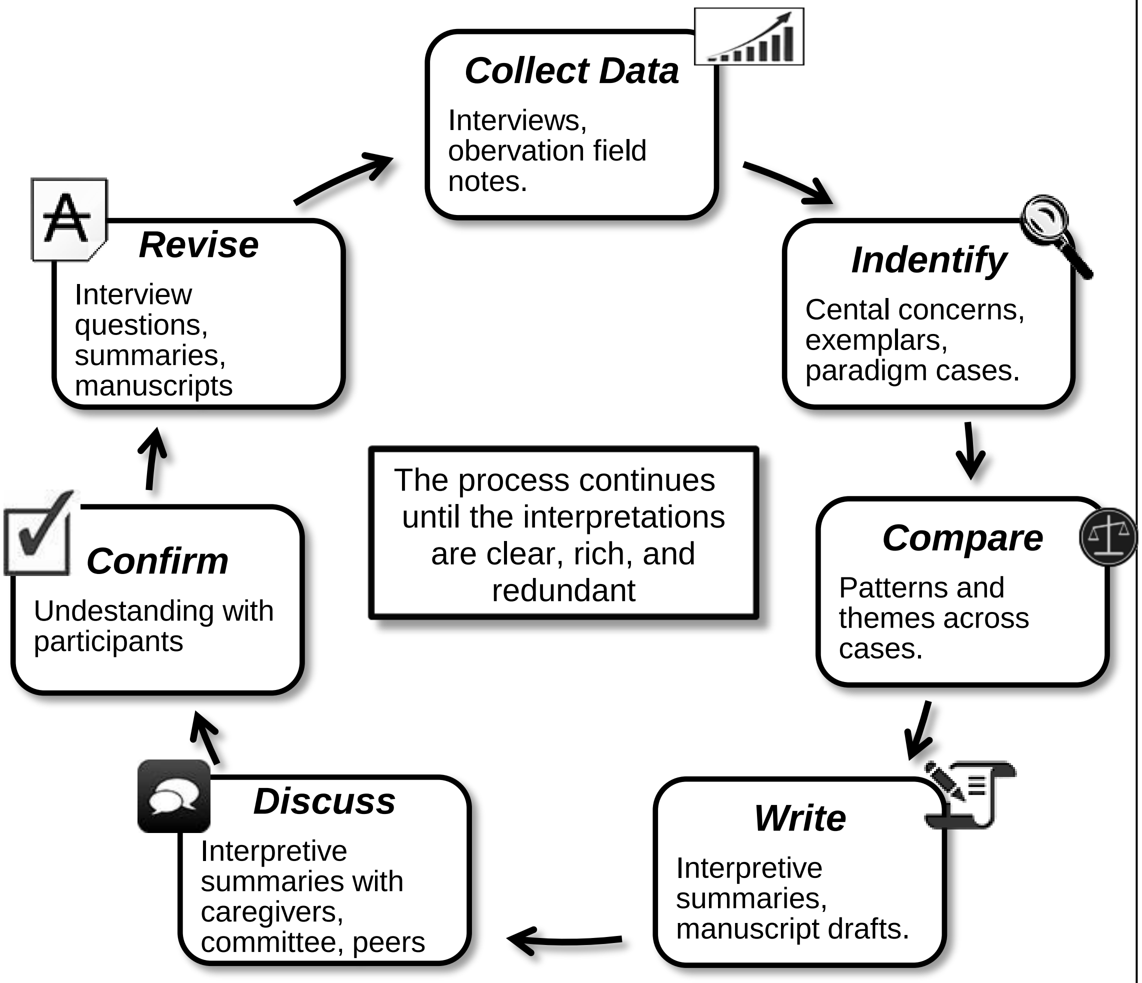
Recruitment and data collection ended when themes seemed consistent, clear and redundant (Benner, 1994; Crist & Tanner, 2003). Interviews (not observation sessions) were digitally audio recorded, using two recorders in case of malfunction. The interviews were transcribed verbatim and then checked for accuracy. At each interview $20.00 cash was given to the caregiver to help ameliorate any costs incurred for caregiving by others during the interviews.

Data Analysis

The ultimate goal of interpretive phenomenology is to gain understanding of the meaning of a phenomenon among a group of participants (Benner, 1994). Analysis in this tradition is based on the concept of the hermeneutic circle: an ongoing process of seeking understanding through interviewing, reading transcripts and field notes, interpreting transcripts, and writing interpretive summaries (Crist & Tanner, 2003; Welch, 1999). The steps of the analysis are outlined below and presented visually in Figure 2.1; however, it is important to note that the steps were not necessarily followed in sequence. Interpretive analysis is an iterative process which builds on the knowledge that is accrued through research progression.

An important early task in interpretive phenomenology is to "…leap into the circle, primordially and wholly..." (Heidegger, 1962, p. 316). This was taken to mean that in my work I needed to recognize my background, presuppositions, and prejudices (Benner, 1994). Disregarding my background risked limiting data analysis by ignoring my potential contributions (Heidegger, 1962) and is inconsistent with the interpretive phenomenological method. As I engaged in my research I considered my background, including (but not limited to) my experience as a White woman, a gerontological nurse practitioner, a farmer, and the daughter of a parent with dementia. To this end, an audit trail, “Personal Response Documentation” was maintained. This documentation allowed for journaling about the study, participant interactions, self-revelations, and insight into prejudices (Rodgers & Cowles, 1993). This reflective stance will helped inform the analysis but not dominate it (Doyle, 2013).

Figure 3.1. The Interpretive Phenomenological Analysis Approach



Adapted from Crist and Tanner (2003); Benner (1994 & 1996); Packer (1989)

Analysis began after the first interview and continued beyond data collection. After each interview, the context of the caregiver's experiences was described. Once an early understanding of a caregiver's situation was grasped, the transcript was read for emerging themes: lines of inquiry, central concerns, exemplars, and paradigm cases. Lines of inquiry were questions that emerged from analysis of early transcripts (e.g, what does loss mean for these caregivers) and shaped future interview questions (e.g., is "grief" a something that happens prior to death?). Central concerns are themes that illustrate how a participant is situated her culture and the historical experiences that shape the meaning of dementia-related changes for her. In this study, a central concern was how the history of slavery and limited health care services influenced caregiving strategies, both in the past and in the current situation.

Exemplars are excerpts from interviews that aptly captured the meaning of dementia-related changes for the caregivers, and paradigm cases are especially compelling stories that can be used to compare with other cases (Benner, 1994; Crist & Tanner, 2003).

Data collection continued until clear and redundant themes were found in the transcripts. Throughout the process, I continued with interpretation, summarization and writing. Notes from observations and the audit trail were folded in to the interpretations and final summaries of the findings produced.

A manuscript was then prepared to communicate the findings to professionals who study and work with families with dementia.

The qualitative analysis program, Dedoose (SocioCultural Research Consultants, 2014), was used assist with the analytic process. This program facilitates qualitative analysis through theme identification and coalescence. The secure on-line platform allowed my dissertation committee to view transcripts and provide analytic consultation.

Rigor

Qualitative researchers aim to demonstrate scientific rigor by establishing the trustworthiness of their findings. Like validity and reliability in quantitative studies, the efforts to provide trustworthy findings assure consumers that this research presents an honest representation of the findings. Two approaches were used to assure rigor in this study: Lincoln and Guba’s (1985) elements for trustworthiness and de Witt and Ploeg’s (2006) framework for rigor in interpretive phenomenological research. Lincoln and Guba (1985) put forth four qualities by which a study can be evaluated for trustworthiness: a. credibility, b. transferability, c. dependability and d. confirmability. These will be discussed next, followed by a discussion of de Witt and Ploeg’s (2006) criteria.

Credibility. To increase the likelihood that this study will result in credible findings, prolonged engagement, persistent observation, triangulation, peer debriefing, negative case analysis, and member checking was used. Prolonged engagement involves developing a deep understanding of the participants' culture and community, the context of their lives. This was achieved through spending time in the community, building trust and recognizing my own values and assumptions. Activities of prolonged engagement for this study began in 2011 when I started volunteering in the African American community as a nurse practitioner in a community clinic. For the last two years, I have been an active member of PreSERVE, a coalition of community members and academicians that work to promote cerebrovascular health in the African American community. I completed Black Studies coursework at Portland State University to further my understanding of the historical and cultural forces that shape the African American caregiving experience. As discussed above, I recognize that I have a limited understanding of African American caregivers' lives. I therefore engaged the help of community advisors to inform me and keep me on course (Lincoln & Guba, 1985).

Persistent observation meant that I remained thoughtfully engaged and curious throughout the interviews. Efforts were made to keep the interviews open long enough to procure information, but at the same time respect the energy levels and time commitments of the participants. Only one interview was abbreviated due to caregiver fatigue and cold symptoms. Lincoln and Guba (1985) advise making conscious efforts to identify salient lines of inquiry, but at the same time sift out irrelevant information. Persistent observation occurred both in the interview and analysis processes. Analysis of interviews and observation field notes guided me towards the relevant themes to pursue in future interviews in this study.

Observation reports, interview data, CAC commentary and field notes were triangulated to identify consistent or contrasting themes. These comparisons added dimension to the study and provided insight into the trustworthiness of the data and subsequent publications by identifying potential distortions and complementary themes. The contributions of the CAC were especially insightful in that they verified my hunches about emerging themes and assisted me in crafting follow-up interview questions that were more culturally appropriate. For example, I asked participants if they felt their family member with dementia was *gone* even though the PWD was still alive. The CAC and I discussed this concept of *gone* in depth. The CAC (2014, January 12) advised that the term *gone* meant physically dead and caregivers would have trouble understanding this question. After this discussion, I decided to continue to use the question, but I had a deeper understanding of the meaning of the term *gone* and could appreciate the difficulty caregivers might have answering this question. In some cases, I substituted *gone* with *still here*. These valuable conversations were coupled with in-depth discussion of the transcripts and field notes with my dissertation committee and dissertation peers to support the trustworthiness of the findings (Lincoln & Guba, 1985; Patton, 2002).

Peer-debriefing with colleagues challenged my assumptions. Due to the cross-cultural nature of this study, it was imperative that I recognized my own conscious and unconscious biases, motivations and interpretations. Peer debriefing helped me in my efforts to remain reflexive and conscientious throughout the research process. Peers thoughtfully examined my work and posed critical questions that stimulated consideration of my values, assumptions, and ethnocentric views (Lincoln & Guba, 1985). For example, in discussion groups my peers examined my knowledge of the African American community and challenged me to consider how I, as a White woman, could understand the experiences of African American caregivers.

Negative case analysis involves examining cases that don't fit the patterns of the other cases. In this phenomenological study, negative cases were scrutinized for competing central concepts and exemplars. The data from these alternative cases were used to consider the lines of inquiry and the fit of the interview questions (Crist & Tanner, 2003; Lincoln & Guba, 1985). In this study, a case involving a care-recipient who was terminally ill was contrasted with the rest of the cases in which death was a more remote concern.

Member checks, where participants review the interpretive output, allowed me to clarify information from earlier interviews. Lincoln and Guba (1985) asserted that this is one of the most important aspects of evaluating trustworthiness because the participants, the source of the data, were able to verify or refute my analyses and interpretations. Through member checks, the participants corrected my assumptions, filled in gaps in understanding, and assisted me in analysis and of the interviews. Member checking started with the first interviews and continued through the remained of the study (Benner, 1994; Lincoln & Guba, 1985).

Transferability. Transferability involves providing thick and interesting descriptions of the study context, design, and findings so that consumers can make informed decisions about the utility of the findings in similar settings and studies (Lincoln & Guba, 1985). This will be a study of a small group of people in Portland, Oregon and is therefore not strictly generalizable to all African American caregivers. Nonetheless, a solid description that resonates with readers can provide consumers with the materials needed to consider and link the meanings other caregivers, in different settings, ascribe to dementia-related changes. Patton (2002) cautions against describing the study in fine detail, but argues for providing eloquent descriptions from which consumers can understand the study context and, for researchers, to replicate the study in other environments. The findings of this study will be published in a peer-reviewed journal.

Dependability. Dependability (Lincoln & Guba, 1985) was demonstrated in this study by maintaining three audit trails: methodological, contextual and personal responses. These audit trails were used to track decisions and responses throughout the study process (Rodgers & Cowles, 1993). The methodological audit trail allowed for documentation of events and decisions that address study design. This audit trail was started in September 2012, when the study was being planned. During analysis, this trail was maintained within in the Dedoose (2014) database. The personal response audit trail provides a platform for me to write about my feelings, assumptions and questions. Acknowledgement and consideration of my background is consistent with the Heideggerian philosophical stance that embraces my experience. This trail was also started in September 2012. The contextual audit trail, also maintained in the Dedoose database (2014) included descriptions of the context of the interviews and events that affected the interviews (such as interruptions from the care-recipient). These audit trails were used to reflect on and correct the research course and to provide evidence of the substantial efforts that were used to maintain trustworthiness in this study.

Confirmability. Confirmability also is tied to maintaining a careful audit trail, but goes farther by requiring that raw data and other records be retained long enough to contrast with the final findings (Lincoln & Guba, 1985). The analysis process in interpretive phenomenology has a back-and-forth quality in which early transcripts are compared to later transcripts. This iterative approach is consistent with Lincoln and Guba's (1985) concept of confirmability in that transcripts will be read repeatedly and discussed with participants, peers and committee members to ensure understanding.

In addition to using Lincoln and Guba’s (1985) framework for ensuring rigor, two of de Witt and Ploeg’s (2006) guidelines expressing rigor in interpretive phenomenological research were incorporated into this study: Balanced integration and actualization.

Balanced integration. Balanced integration was demonstrated by clearly identifying the study’s philosophical foundation and then linking the findings to this foundation. The philosophical orientation of the study, and the guiding philosophical concepts, were explicated and integrated throughout the research process. The participants’ voices and my interpretations are consistent with the philosophical base. In this study, the philosophical orientation towards Heideggerian interpretive phenomenology is discussed throughout the chapters in this dissertation, woven into the study methods, and was incorporated into data analysis and dissemination. For example, the above discussion of analysis specifically discusses my consideration of my background in the study. This is consistent with the Heideggerian stance of consciously honoring and incorporating one’s background into analysis. In addition, analysis of the interview data was based on the hermeneutic circle and evidence of the interpretive phenomenological approach can found in the interpretive summaries and publications. Quotations from the caregivers are used in paradigm and exemplar case descriptions to illustrate the authenticity of their words. Publications resulting from this study will begin with a brief synopsis of the philosophical underpinnings and rational for positioning this study in this tradition.

Actualization. De Witt and Ploeg (2006) discuss actualization as respecting that the phenomenological process does not end with a study's conclusion. In this study, actualization will be promoted by discussing how study findings can be used in both the clinical and research realms. For example, findings could be used to assist a provider in an empathetic conversation or mutual goal-setting with a caregiver (see Chapter 1, "Implications for Nursing") (Kearney, 2001). Researchers could also use the findings to develop measures for future studies, such as quantitative studies that address the meaning caregivers ascribe to dementia-related changes.

In summary, Lincoln and Guba's (1985) time-honored methods for ensuring rigor was complemented by DeWitt and Ploeg's (2006) customized approach to rigor in interpretive phenomenological research. The combination of these two approaches exhibited careful attention to the process of establishing rigor within the philosophical context of Heideggerian hermeneutics.

Ethical Considerations

The history of research with African Americans in America is marked by torture during Slavery, fear-mongering and cruelty during the Jim Crow years, manipulation and mendacity with the Tuskegee Syphilis Study, and mistrust in the present era (Gamble, 1997). In light of this history, every effort was made to engage in honest and thoughtful research with these participants, including careful adherence to Institutional Review Board (IRB) rules and guidelines. Caregivers were advised that, by law, child and elder abuse must be reported. My plan was to refer any caregivers who appeared unduly distressed by the emotional nature of the interviews to the appropriate services (see Appendices I and J). However, the only caregiver that appeared upset by the interview assured me that she had her own established counselor. Additionally, she, like many of the caregivers in this study, commented that she found telling her story helpful (Eide & Kahn, 2008). Finally, due to the sensitive nature of this study, I and my committee understood ethical issues not stated here could arise and we were prepared to entertain the unexpected. For example, in the middle of one interview, the care-recipient joined me and the caregiver. My committee and I discussed the nature of his involvement and whether or not this was considered an "observation."

Protection of Human Subjects

Guidelines for conducting ethical research and protecting participant privacy will be carefully adhered to in this study. I and my community advisors completed Responsible Conduct of Research training and Conflict of Interest evaluation through OHSU's Integrity Office. Institutional Review Board (IRB) clearance at OHSU was secured prior to embarking on the research study.

One potential concern is that the identity of the caregivers could be revealed in the exemplar and paradigm cases. The African American community is a small and members of the community often know, or know of, each other (Community Advisory Committee, 2014, February 21). Damianakis and Woodford (2012) recommend overt consideration of these concerns in order to tailor efforts to ameliorate the risk of confidentiality breach. For this study, pseudonyms will be used and physical descriptions disguised so as not to reveal caregiver identity in presentations and publications. Furthermore, participants will be informed in the consent process that, due to the size of the small community, there is a risk, albeit small, that others in the community will recognize their narratives.

A transcription service that adheres to OHSU privacy policies was employed to transcribe the audio recordings. All interview transcripts were de-identified and pseudonyms were used for any analysis or reporting purposes. All interview data and recordings were kept on my password-protected H drive. Hard copies of consents are secured in locked files. Original data recordings will be secured for the amount of time required by the IRB.

Dedoose (2014) an online qualitative research system, was used for analysis. De-identified transcripts were uploaded to Dedoose (2014), where access is tightly controlled and data transmission is fully encrypted to ensure confidentiality. Data is backed-up regularly to protect against loss.

Strengths and Limitations

The strengths and limitations in this study are for the most part, twofold: first, there are issues around my ethnic and professional background and second, the dementia diagnoses in this study were based primarily on information from the caregivers. These strengths and limitations could affect the quality of the study and are discussed here.

There are known cultural and racial differences between me (White) and study participants (African American) which can be considered a strength of this study. For example, the participants may have felt more comfortable revealing sensitive information to someone outside their close-knit community. As an outsider, I assumed a student role in which the participants could impart instruction about common norms, practices and beliefs (Adamson & Donovan, 2002; Ochieng, 2010). As an investigator outside the culture under study, I was also able to maintain my perspective as a researcher without engaging (for the most part) in an expected role within this cultural group (Field, 1991).

Alternatively, the cultural divide could have been a limitation to this study. I am of White heritage and not from the African American community in Portland. This may have affected the depth of information gleaned from the participants in that they may not feel comfortable talking about their feelings in-depth with a person of a different race (Adamson & Donovan, 2002). To mitigate this potential concern, I attempted to build trusting relationships in the community two years prior to study initiation. Once the study began I engaged the assistance of my community advisors to facilitate the development of mutual respect between me and the participants (Topp, Newman, & Jones, 2008). All this considered, my CAC (2014, January 12) advised me that this community of African Americans engages with Whites on a daily basis. They felt that my race would not affect the quality of the interviews .

A second identified strength of this study is my background as an experienced gerontological nurse practitioner with an extensive history of working with families with dementia. I am skilled at building trusting relationships with families and can use my therapeutic communication skills to encourage discussion of caregivers' meaningful experiences (Lipson, 1991). With this clinical acumen, I was able to identify signs of caregiver stress and proffer support information as indicated (see Appendix I). If the care-recipient was present (as in the observation sessions), I watched for signs of care-recipient stress (e.g. pacing, repetitive verbalizing) and planned to excuse myself from observations if these signs appeared. However, none of the care-recipients exhibited signs of distress during my visits.

My experience as a nurse practitioner could also be a limitation in that I may find myself slipping into a clinical role. To avoid this, I attempted to maintain a reflexive stance, documented my experiences in my audit trails and debriefed with my dissertation committee and peers.

A second potential limitation to this study was my reliance on caregiver information to identify if the care-recipient had dementia. The literature documents delays of diagnosis for African Americans (Clark et al., 2005) and this was evident in this study. Six of the care-recipients had a known diagnosis of dementia according to caregiver report. The other five cases met the criteria for all-cause dementia (Alzheimer's Disease Dementia Workgroup, 2010), but the diagnoses were not confirmed with cognitive testing, lab studies or imaging.

Conclusion

Chapter 3 describes in detail the approach to this study. The philosophical foundation and rationale for using interpretive phenomenology was discussed. The study method and design were outlined. Rigor and ethical issues were addressed. The study consent forms, interview guide, observation guide and consent forms are all found in Appendices E-H. Because this Chapter 3 closely mirrors the IRB-approved protocol, the protocol is not included in this dissertation. It can be viewed upon request (Lindauer@ohsu.edu).

Chapter 4

Introduction

Like Chapter 2, Chapter 4 is a presentation of the findings manuscript. This chapter contains the third manuscript prepared for this dissertation. The manuscript is preceded by a preliminary page with the title, author information. A standalone summary follows the preliminary page. The remainder of Chapter 4 is the full manuscript. The reference list for the manuscript is embedded in the full reference list at the end of this dissertation.

Findings Manuscript

Table 4.1

Elements of Findings Manuscript

Title	The Meanings African American Caregivers Ascribe to Dementia-Related Changes: The Paradox of Hanging on to Loss
Authors' Contributions	First Author (AL): Study design, all data collection and analysis, manuscript preparation. Second Author (TAH): Design consultation, data analysis, conceptual guidance, editing. Third Author (PW): Design and methodological consultation, analysis, conceptual guidance. Fourth Author (PB): Design consultation, analysis, conceptual guidance.
Funding	Unfunded
Citation	Not applicable

The Meanings African American Caregivers Ascribe to Dementia-Related changes: The Paradox of Hanging on to Loss

(Summary)

Purpose and Aims

The purpose of this interpretive phenomenological study was to understand how African American caregivers perceive and respond to dementia-related changes in their care-recipients. There were two specific aims: first, to understand the meaning African American family caregivers ascribed to the dementia-related changes in their care-recipients with ADRD; and second, to explore African American family caregivers' emotional responses to these dementia-related changes in persons with ADRD.

Review of the Literature

Many caregivers for persons with dementia experience the dementia-related changes as loss and respond with pre-death grief (Collins, Liken, King, & Kokinakis, 1993; Mayer, 2001; Sanders & Corley, 2003). Pre-death grief is associated with several concerning caregiver outcomes, including burden (Holley & Mast, 2009), depression (Sanders & Adams, 2005), and impaired decision making (Fowler et al., 2013). Most of the research addressing pre-death grief focuses on the experiences of White caregivers. Little is known about how African American caregivers perceive dementia-related changes or what their responses are to these changes.

Design and Methods

This was an interpretive phenomenological study. Eleven African American caregivers in the Pacific Northwest (PNW) participated. Each caregiver was interviewed twice in a 6 week period, for a total of 22 interviews. Following this research tradition, caregivers were asked to tell stories about their care-recipients. The meanings of the dementia-related changes were garnered from analysis of these stories. Four caregivers agreed to take part in the observational sessions. These sessions provided insight into the lived experience of the caregivers. All interviews were digitally recorded and professionally transcribed. The observation sessions were not audio recorded, but the field notes were incorporated into the analysis.

Analysis

Analysis was based on the hermeneutic circle. This process involves writing interpretive summaries, grasping initial meanings, and then returning to the caregivers for second interviews. This was an iterative process in which the initial interviews informed the later interviews and observations. Written summaries were reviewed with peers and experts in gerontology for feedback, guidance, and review of findings.

Human Subjects Protection

All data was kept in secure, password-protected computer files. Consents were kept in a locked cabinet at the university. University IRB approval was secured prior to study initiation (#9777).

Results, Discussion, Conclusion

Overall, we found two themes. First, that the caregivers in this study recognized the dementia-related changes and responded by *hanging on* to what remained of the care-recipients' personhood. Second, despite substantial changes, these caregivers recognized that their care-recipients were *still here*. Instead of mourning what they had lost, these caregivers tended to focus on the remaining function and personalities of their care-recipients. There was some sense of loss and burden, but, in general, this was overshadowed by a sense of gratefulness for what the caregivers still had. Caregivers and the Community Advisory Committee (2014, February 22) advised that that this focus on *hanging on* to what is *still here* was influenced by the history of African American values combined with oppression in the US.

These findings are in contrast to the literature which describes the caregiver experience as defined by loss and grief (Moyle et al., 2002; O'Donnell, 2000; Ott, Sanders, & Kelber, 2007). The implications are that health care providers in the PNW can use this information to provide culturally-appropriate care and to prepare these caregivers for the death of their family members with dementia.

The limitations of this study include the fact that the lead investigator is not from the African American community. This may have limited the depth of the interviews and quality of the data. Another concern is that the diagnosis of dementia was based on solely on caregiver report and not confirmed through a review of medical records.

In conclusion, this study provides insight into how African American caregivers understand and respond to changes in their family members with dementia. There continues to be a dearth of research that investigates the meaning African American caregivers ascribe to dementia-related changes. This study narrows that gap.

The Meanings African American Caregivers Ascribe to Dementia-Related changes: The Paradox of Hanging on to Loss

Abstract

Purpose: Using an interpretive phenomenological approach, this study explored the meaning African American caregivers ascribed to the dementia-related changes in their care-recipients.

Method: Data was gathered through 2 in-depth interviews with 11 African American caregivers in the Pacific Northwest (22 interviews). Four caregivers participated in an optional observation session.

Results. Analysis based on the hermeneutic circle revealed that, for these caregivers, the dementia-related changes meant that they had to *hang on* to the care-recipients for as long as possible. Caregivers recognized that the valued care-recipients were *still here* and worthy of attention and compassion. Historical oppression appeared to influence these meanings.

Implications. These findings have the potential to foster positive caregiver-health care provider relations and assuage the burden of prolonged grief disorder in these caregivers after care-recipient death.

The Meanings African American Caregivers Ascribe to Dementia-Related changes: The Paradox of Hanging on to Loss

Introduction and Background

In the United States, 1 in 9 older adults has Alzheimer's Disease or a related dementia (ADRD) (Alzheimer's Association, 2014). For African American families, the rate is even higher: African American elders are almost twice as likely to have ADRD as Whites (Plassman et al., 2007; Potter et al., 2009; Tang et al., 2001). The African American caregivers for persons with dementia also experience disparities in that they have worse physical health outcomes than White caregivers (Kiecolt-Glaser et al., 2003; Merritt et al., 2011), and a higher risk of mortality (Schulz & Beach, 1999). Additionally, these caregivers tend to be less prepared for the death of their family member with dementia, placing them at higher risk for prolonged grief disorders (Hebert et al., 2006). And while African American caregivers have historically limited their use of long term care for aging family members, this trend is starting to reverse (Feng et al., 2011) suggesting increasing burden on families. These issues are particularly concerning in light of the fact that African American caregivers make up a significant portion (approximately 13%) of the US caregiver population (National Alliance for Caregiving & AARP, 2009).

One area of the African American caregiving experience that is poorly understood is the meanings they ascribe to the dementia-related changes in their care-recipients. Alterations in cognitive functioning, personality and physical health in persons with dementia can be emotionally difficult for family caregivers. The changes can be perceived as losses, and a common response to these losses is grief prior to the death of the care recipients, termed *pre-death grief* (Collins et al., 1993; Lindauer & A Harvath, 2014). Pre-death grief contributes to impaired caregiver physical health (Walker & Pomeroy, 1997), depression (Sanders & Adams, 2005), burden (Holley & Mast, 2009), loneliness (Knutsen & Raholm, 2009), domestic violence (Rudd et al., 1999; Sanders et al., 2003), and prolonged grief after the death of a care-recipient (Ghesquiere et al., 2011; Givens et al., 2011; Schulz et al., 2006). Higher levels of caregiver pre-death grief are also associated with impulsive and ineffectual problem-solving techniques (Fowler et al., 2013). However, most of the literature that addresses pre-death grief focuses on the experiences of White caregivers; knowledge of this phenomenon in African American family caregiver is limited.

Purpose. Only a few studies have included African American caregivers in their investigations of pre-death grief (Diwan et al., 2009; Lindgren et al., 1999; Owen et al., 2001; Ross & Dagley, 2009; Sterritt & Pokorny, 1998), and there is conflicting evidence about whether pre-death grief is a common response to dementia-related changes in their family members (Owen et al., 2001; Ross & Dagley, 2009). The African American pre-death grief experience is poorly understood, and it is unclear how relevant this concept is for these caregivers. Therefore, in order to garner a broader perspective of the their experience, we sought first to understand the meaning African American family caregivers ascribed to the dementia-related changes in their care-recipients with ADRD, and second to explore their emotional responses to these changes.

Design and Method

Toth-Cohen (2004) emphasizes that use of methods which identify a singular truth contributes to the myth that cultural differences are distinct and dichotomous. As such, we chose an interpretive phenomenological (IP) approach (Benner, 1994; Crist & Tanner, 2003), which respects the existence of multiple truths yet recognizes that common themes can emerge from caregivers of similar and divergent backgrounds. This study is grounded in the hermeneutic orientation that the caregivers' experiences are embedded in their everyday lives and shaped by their culture. The meanings caregivers ascribe to dementia-related changes and their reactions to these changes may be taken for granted. The goal in this study was to uncover the tacit meaning of dementia-related changes in care-recipients that is embodied in the caregivers' day-to-day lives (Benner, 1994).

The Community Advisory Committee (CAC). Because the investigators in this study are all White, a Community Advisory Committee (CAC) was engaged to provide expert consultation for the researchers. The CAC assisted with recruitment, provided valuable background information, and discussed interview themes with the investigators. This team consisted of two older African American women from the community. Both women grew up in the African American neighborhood where this study took place. Key informants identified them as ideal CAC members because they are well-known, highly respected members of the community. The lead investigator started meeting with the CAC 18 months prior to study initiation. These early meetings allowed the CAC to educate the lead investigator about the African American community, appropriate comportment and study design. An important question early in study design was which term (“Black” or “African American”) was best suited to this study. They advised that the older caregivers would prefer “African American”; thus, this term was used throughout the study and in this manuscript.

Study Participants. The target population was African American family caregivers of persons with mild, moderate, or severe dementia in the Pacific Northwest (PNW) within 50 miles of the lead investigator. Purposive sampling was used to recruit caregivers who fit the study criteria. The study was advertised with flyers placed in the community. CAC members, contacts from the lead investigator’s volunteer network, and staff from the university dementia center provided contact information for potential participants. The majority of the caregivers contacted by the researcher agreed to participate in the study. Those that did not participate were too busy with caregiving (3), were the previous caregiver of a deceased relative (1) or were White (1).

Eleven caregivers participated in the study. A subsample of caregivers (4) agreed to take part in an optional observation session.

Because of the small numbers of African Americans in the PNW, inclusion criteria were purposely broad. To be included in the study, caregivers had to identify as an African American family member of a person with dementia--either biologically related or fictive kin (individuals that are not related, but nonetheless are considered family members (Stewart, 2007). Eligible caregivers provided four or more hours of care to a family member per month and had been in that role for at least one month. Caregivers who met the criteria were then asked about their care-recipient. In order to participate in the study, the care-recipient had to have dementia. The Alzheimer's Association's Criteria for all-cause dementia (Alzheimer's Disease Dementia Workgroup, 2010) were used to determine whether the care-recipient had dementia. These criteria include cognitive and behavior changes which: (a) interfere with work or social activities, (b) represent a decline from previous functioning, and (c) are not explained by delirium or major psychotic disorder. Additional characteristics, as described by persons with dementia or family members, include impaired ability to retain new information; impaired reasoning, visual-spatial, and language skills; and personality change. Potential participants who had good evidence that their family member met these criteria were included in the study. Consent forms were carefully reviewed and signed at the first interview. This study received the university's Institutional Review Board (IRB) approval.

Procedure. In-depth interviews were conducted with each study participant twice over a 6 week period. Four participants were observed caring for their family member with dementia between the two interviews. Minimal demographic data were collected in order to both describe the sample and protect the confidentiality of these individuals who live in a relatively small community. Caregivers were given $20 cash per interview to reimburse them for any caregiving costs while they were engaged in the interviews.

Interviews. The lead investigator conducted all of the interviews and observation sessions. In order to tap into the caregivers' authentic experiences, the interviews began by asking caregivers to tell a story (Benner, 1994), for example: "Please tell me a story about what your mother was like when you were growing up." A series of prompts were developed and used as needed to elicit stories that uncovered the caregivers' perceptions of dementia-related changes and the influence culture had on these perceptions (Rubin & Rubin, 2005). The emergent nature of design of this study allowed for the evolution and alteration of questions as lines of inquiry were identified in the interviews (Benner, 1994; Crist & Tanner, 2003).

Before the second interview was conducted, the lead investigator read the transcript of the first interview and wrote an interpretive summary. These summaries were discussed amongst the research team members to identify themes and compare interpretations. In the second interview, key themes from the first interview and observation (if applicable) were reviewed and clarified. Interviews took between 35 and 90 minutes and were digitally recorded. The interviews continued until repetition in the themes emerged from subsequent interviews, indicating that data saturation was achieved.

Observations. In IP, an investigator attempts to understand the ready-to-hand (taken-for-granted) experiences of the participants (Plager, 1994). Therefore, non-participant, unstructured observation was used to facilitate understanding of the participants' lived experiences through witnessing their caregiving in the context of their daily lives. Seven participants agreed to take part in the observation sessions, but two canceled due to illness and one canceled due to unplanned out-of-town travel. Dimensions of the caregiver/care-recipient relationships not identified in interviews, such as the degree of care-recipient cognitive impairment, were revealed through observing families in the privacy of their homes (Briggs et al., 2003). During observation, the interactions, dialogue, cues, tone, affect, and non-verbal exchanges between the caregiver and recipient were noted as the dyad engaged in a familiar task (e.g., getting dressed). No audio or video recordings were made during observation; instead, field notes were taken (Creswell, 2009) and included in the analyses.

Analysis

Analysis in IP research is based on the concept of the hermeneutic circle: an ongoing process of seeking understanding through interviewing, reading transcripts and field notes, interpreting transcripts, and writing interpretive summaries (Crist & Tanner, 2003; Welch, 1999) (Figure 3.1). This is an iterative process which builds on the knowledge that is accrued through research progression.

Analysis of the interview transcripts began after the first interview and continued beyond data collection. Field notes describing the context of the caregiver's experiences and the investigator's thoughts, feelings, and hunches were also transcribed and included in analysis. The transcripts were initially read while listening to the audio files. Next the transcripts were read for emerging themes: lines of inquiry, central concerns, exemplars, and paradigm cases. Interpretive summaries of each interview were written after the first interview and re-written after the second. Finally the interpretive summaries were distilled into a final summary (Crist & Tanner, 2003).

Rigor. Prolonged engagement, triangulation, peer debriefing, negative case analysis, and member checking were used to increase the trustworthiness of our findings (Lincoln & Guba, 1985). In order to build community trust, the lead investigator volunteered in a local clinic for 2 years prior to study initiation and continued this work after study completion. Once the study began, interview data were triangulated with observation data and the feedback from the CAC. In order to maintain an open and reflexive stance, an audit trail documenting personal responses and perceptions was maintained. The process of discussion and journaling provided insight into taken-for-granted assumptions and prejudices (Rodgers & Cowles, 1993). Colleagues offered feedback and posed critical questions that stimulated consideration of values, assumptions, and ethnocentric views of the lead investigator (Lincoln & Guba, 1985).

Ethical considerations. The history of research with African Americans is marked by torture during slavery, fear mongering and cruelty during the Jim Crow years, manipulation and mendacity with the Tuskegee Syphilis Study, and mistrust in the present era (Gamble, 1997). In light of this history, every effort was made to engage in honest and thoughtful research with these caregivers. This included honest representation of their stories about the history of slavery and how this affected their caregiving, as discussed in the following section (Holloway & Freshwater, 2007).

Findings

Background. This study took place in the Pacific Northwest (PNW) region of the United States. In the early 1900s, despite exclusionary laws and the unwelcoming environment of some states, African Americans gravitated to this region as the railroads established robust business in the western states. Many of the first African Americans in this region were “red caps,” gentleman who catered to the needs of White travelers on the train systems.

Along with the chefs, housekeepers, and other service providers to the train customers, merchants and other professionals were counted among African Americans in the early years of the PNW (Tuttle, 1990).

In the 1940s, the region’s population swelled when shipyards were built to produce ships for World War II. Due to high demand, workers were transported to the PNW by the thousands on “Magic Carpet Specials,” trains used solely for bringing workers to the PNW (Tuttle, 1990). In Oregon alone, the African American population grew from 2,500 in 1940 to over 21,000 by 1945. Overcrowding was problematic and eased by the production of temporary housing, including the construction of Vanport, the largest wartime housing project in the US. Vanport was devastated by a flood after the war, forcing 5,000 African American survivors into small neighborhoods. The space available to these flood victims was constrained by the practice of forbidding purchase of housing by African Americans anywhere outside tightly controlled neighborhood boundaries (Taylor, 1981).

Caregivers in this study described the racial tensions of the time, noting that the local (White) citizens hoped the African American citizens would return to the South. To this day, the caregivers in this study perceived this flood not as an act of nature, but as purposeful effort to “cleanse” the region of African Americans.

The majority of the caregivers interviewed for this study came from the South during the 1940s to work for (or near) the shipyards. The values of industriousness, primacy of family, and Christian faith (Hill, 1999) were brought with these families and continue to be important to this day. Additionally, despite being far from the South, these families found racism in the PNW. From an active Ku Klux Klan presence (25,000 members in Oregon alone; Chalmers, 1965) to the current gentrification of today's urban African American neighborhoods, these study participants and their families experienced both community acceptance and rejection in this "peculiar paradise" (McLagen, 1980, p. 2) in the PNW.

Demographics and functional status. All the caregivers in this study were African American. All the care-recipients were African American with the exception of two White care-recipients. One of the 11 caregivers was a man. Nine of the care-recipients were biological family members (e.g., mothers) and two were fictive kin. Annual income ranged from under $5,000 to over $75,000. Table 4.2 provides demographic information.

Many of these care-recipients had moderate to severe dementia, based on the reports of their caregivers. Behavioral symptoms of dementia included agitation, apathy and wandering. Word-finding problems, withdrawal, and forgetfulness limited communication with family members. Some care-recipients were disinhibited, causing the caregivers to feel embarrassed by their behaviors. Memory loss and impaired executive function were common. The majority of the care-recipients (8) lived with their caregivers; the rest, in assisted living facilities (ALFs). All of the care-recipients were dependent on others for meal preparation and needed help with bathing and toileting. All but one of the care-recipients had a single, primary a caregiver. The primary caregivers were interviewed for this study. One care-recipient had two family caregivers who shared the role and both of these caregivers were interviewed.

Table 4.2

Participant Demographics

	Average	Range
Caregiver age	59	43-81
Care-recipient age	79	55-93
Years caregiving	6.5	2-13
Hours caregiving/week	30	4-84

Overview. Broadly, this study found that these African American caregivers perceived the dementia related changes as relatively insignificant in the wider scheme of their lives and values. More specifically, we identified two important themes. First, because the caregivers placed high value on their elder care-recipients, they worked to maintain their care-recipients' current abilities and status in the family. This theme was entitled *hanging on*. Second, the dementia-related changes meant cognitive and functional decline and loss, but the caregivers appreciated the fact that the care-recipients were still present and important members of the family. This theme was labeled *changed, but still here*. These themes and study implications are discussed in detail below.

Findings. A paradigm case was used to understand, interpret and discuss key themes across the other cases (Crist & Tanner, 2003). The paradigm case below illustrates the meaning one family gave to the dementia-related changes in their elder. This case was chosen as the paradigm case because it was a compelling example of how many caregivers in this study understood the dementia-related changes (Benner, 1994).

> Two caregivers from the same family cared for their elder. To escape oppressive racial discrimination, the elder (as a young man) moved from the South to work in the PNW shipyards. He raised his family in the PNW, placing high value on keeping the family together. When he began to lose his memory, the family directed its efforts to keeping him as “one of the team.” Everyone on the team had job, and the elder’s job was to “stay alive.” The dementia-related changes for this care-recipient (poor short term memory, impaired executive function, word-finding difficulty, functional impairments) were of minor concern for this family. They saw him as “aging out” but they focused on keeping him healthy: “Even at his age, I think I could get his body toned a little better.” They felt that he “doesn’t seem to have health problems” and was “lucky” that he didn’t have cancer. For this family, cancer meant certain death, which was abhorrent to them: “…I don’t want to see him leave this earth at all.” The team worked to keep him healthy and engaged for as long as possible. They saw him as a “little quieter” and missed the fact that he could no longer go fishing with them. They expressed worry and described feeling protective of him, but they didn’t feel substantial distress. They appeared grateful for the fact that he was still an active part of the family. What was important for this family was that the elder could still spend time with the family and sustain his valuable role as “the wise one,” telling family stories that kept the past connected with the present.

This story was chosen as a paradigm case because it addresses common themes and represents the experiences of other caregivers in this study. For these caregivers and the others in the study, what was most meaningful was not what had been lost, but instead, what had *not* been lost. Instead, of focusing on the losses and decremental changes, the family was *hanging on* to the elder they still had. For example, they appreciated the fact that he could still accompany the family to the local garden and go on outings with them, “I think he likes running around with us.” They enjoyed being with him and minimized the dementia-related deficits. They did not deny the fact that he had changed, but they were grateful for the fact that he was *still here*: “I’m seeing him get older, okay, like we know the memory is going here. That’s where it’s heading to. But…I look at him, and I go okay, he’s enjoying this moment right now.”

These paradigm caregivers also made reference to their faith. They felt as though a “higher power” and deceased family members were “watching over him,” keeping him safe. Along with other caregivers in this study, they talked about the Biblical instructions to “care for the elderly,” and hoped, “God willing” that this elder would “make it to his next birthday.” While not the focus of this study, all the caregivers made reference to their Christian faith. The church and the Bible were important forms of sustenance and guidance for them. The CAC (2014, January 12) explained, “Because we believe in life…we believe in hope and we believe in the *Bible*—we truly believe all that.”

In the hermeneutic tradition, analysis and interpretation of the paradigm case provided insight to the meanings we identified in the other 10 cases. We found that most of the caregivers' expressed thoughts, feelings and values similar to those in the paradigm case. However, unlike the paradigm case, many of the caregivers felt unduly challenged by their work. They seemed to live in the middle of a paradox: *hanging on* to what was *still here*, but grappling at the same time with burden and loss. These themes and challenges are discussed next.

***Hanging on*.** "Way back when…even in the struggles, and slavery, all we had is each other. So that's why we hang on to each other." This caregiver explained that the history of enslavement and oppression shaped these AA caregivers' values. Specifically, the caregivers in our study placed high value on keeping the family together and *hanging on* to the elder with dementia for as long as possible. They recognized that their care-recipients were losing function, and some even recognized that their care-recipients were close to the end of their lives, "I know that my mom may not live, be here forever." For the most part, however, the caregivers worked to preserve the independence, dignity and personhood of their family member with dementia.

Like the paradigm case, caregivers used strategy of teamwork to *hang on* to their care-recipients. The "teams" listened to stories of the past, spent time in "fellowship" with the care-recipients, and dined out with them to keep them engaged and active. And while the caregivers were able to see that the dementia had caused decrements in cognition and function, many of them did not seem particularly distressed by the changes. Instead, they expressed gratitude for what remained.

This is not to say the caregivers did not have a sense of burden, because many of them did. Caregivers spoke of feeling tired, “it just wears on you.” Some caregivers felt a great deal of responsibility for making important decisions for their care-recipients and were frustrated that the care-recipients could no longer advocate for themselves: “...if somebody disrespect her, she would want to hit ‘em, or she would want to knock the mess out of her husband. But she’s not nothing near that like she was before.” These caregivers described having to be the decision-makers as, “not easy,” and “overwhelming: “It’s just really tough…ah when it comes to her not being able to help me make decisions for herself.”

The emotional response to this burden was for most part, frustration. Caregivers reported feeling “flustrated,” [sic], “sad,” and “pissed.” Caregivers felt that the demands made them feel older: “…you have all this responsibility and worry and stress. It does make you old.” Caregivers also spoke of physical ailments such as diabetes, hypertension and heart disease. These findings suggest that while these caregivers worked to *hang on* to their family member with dementia, they were also vulnerable to the strain of the work. Even so, most caregivers were ambivalent about seeking long-term care placement. A few were considering it at the time of the interviews, but, in general, it wasn't an option many actively entertained.

In IP, important passages ("exemplars") help explain a phenomenon (Crist & Tanner, 2003). The challenge of *hanging on* while at the same time feeling burdened is evident in the following exemplar.

> In order to maintain her impaired family member in an independent facility, this caregiver worked from morning to night caring for her, only leaving her at bedtime: "I give her night medicine…and she sleeps through the night and then I'm back." Despite this heavy workload, this caregiver felt as though she is fulfilling her natural role: "…you're taught this, you're programmed for it. You just step into the role…yeah, it's an easy thing to do." She talks about her sister with affection and appreciates her "ideas, her happiness." But when pressed, she is aware of the burden and loss of personal freedom, "Everything is lost to you almost because you're concentrating on that person and the only time you have some time off is when you just actually steal it, you have to take it." This caregiver described managing her challenges with her faith: "We have faith that you will make it through this. You have faith that you can be healed. You have faith that everything will be peaceful in your life. And so we still rely on that."

Other caregivers in this study also talked of this paradox—of feeling like they are fulfilling an important role for someone they cared deeply about, but also feeling burden and loss. Caregivers often turned to their faith to ameliorate their burden and help them maintain the vitality of their care-recipients, "I pray a lot and ask Him for guidance. I couldn't do this job without Him." Like the caregivers in the paradigm case, they felt that God helped the caregivers *hang on* by watching over, protecting, and blessing their care-recipients.

Despite the fact that many of the care-recipients were quite impaired, the caregivers didn't focus on end-of-life concerns. They recognized that at some point the care-recipient would die ("Eventually something will happen…"), but for the most part, however, these caregivers directed their attention to the present "blessings." They talked about "moments of joy," "at least I have her," "I am glad he can still do some things" and "I'm blessed because my mom is able to still talk." For these caregivers, what was important was to keep the care-recipients healthy, safe, content, and, most importantly, to "keep your family together for as long as you can."

Changed, but still here. The caregivers recognized the dementia-related changes in their care-recipients, but they also emphasized that their care-recipients were *still here* and important members in family life. The majority of the caregivers pointed out the care-recipients were "still sharp," "still ticking," "still here," and "still around."

Importantly, while the care-recipients were changing, many of the caregivers focused on the preserved capabilities and personality traits and described the care-recipients as being *still here*. Caregivers pointed out that their care-recipients still enjoyed life. They participated in church and community events, family parties and outings, and engaged in their hobbies such as singing, playing cards, and telling stories. The caregivers appeared to value the very presence of the care-recipients, despite their impairments: “It’s a blessing to have her still here.”

Nonetheless, caregivers did acknowledge that their care-recipients were “slowing down,” “declining,” and “deteriorating,” that their personalities and functional abilities were changing with dementia progression. These changes often meant that the care-recipients were turning into children, that the caregivers were losing their care-recipients, or both.

Role change was not particularly evident in the paradigm case, but was a substantial issue for other families. One niece spoke of her aunt: “it’s almost like they revert back to a kid. You got to do everything for them…” Similarly, a wife felt as though “you’re raising another child again.” The role changes meant that the caregivers they had to adapt, but they were not overly distressed: “So now you gotta learn, need to do the things that she needs done now.” The CAC (2014, February 21) explained that these caregivers may have taken their work in stride because the history of AA mistreatment and exclusion prepared them to take care of each other. A caregiver explained:

> We were there for the sick. We were there for the babies. We were there for the White people’s babies. We were there for their – you know, anything that we had to do, they kind of did it. I think it’s just the caring nature that’s just in us, that just passed from generation to generation.

Along with witnessing regression, caregivers felt as though they were gradually losing the personhood of the care-recipients they once knew. As a consequence, some caregivers worried about their care-recipients and felt protective of them. In contrast with the paradigm case, others felt a deep sadness about the changes: "I sometimes sit here and I look at him in quiet moments or when he is sleeping and I'm like, 'What happened? Where are you?'" But caregivers also recognized that the care-recipients were *still here*: "It's her but it's a lesser her."

Despite these losses, these caregivers did not think of their care-recipients as "gone." While the caregivers missed meaningful conversations and social outings, such as going out to "have a beer at the bar, play poker…" they tended to dismiss those changes and instead, highlighted the capabilities of the person that remained. They also experienced bittersweet moments when the "real" care-recipient would peek through. And while those were moments of joy, they also brought into sharper relief how much of the "real" person had been lost. One daughter's story is an exemplar of this phenomenon:

> One night, the mother with dementia went to a senior-center party. Earlier in the evening (while the daughter was still at work), the granddaughter helped the mother get ready for the event. When the mother returned home later that evening, the daughter was surprised, "I was like, '*where* have you been and *what* do you have on?' She was like, 'oh, we had a party!' She had put on her sequin dress shirt and her slacks and her pearls. She had her beads on; she was dressed and ready to go for the party! It was sad because I know that was the mother that would have done that in a heartbeat. She'd put her good stuff on and, you know, get dolled up and get ready. It was like a piece of that I saw but then you don't see it every day."

For these caregivers, the re-emergence of the care-recipient's pre-illness self was a welcome suspension of the dementia-related changes. However, once the person with dementia reverted back to their present-day state, the losses seemed more pronounced. Another caregiver explained that if she knew what made the "real" care-recipient come back, she would do whatever was needed to make that happen: "If you knew, you could do it again. If I knew if she ate some beans or something, I would give her beans a lot!" (laughing).

As with the *hanging on* theme, these caregivers struggled with paradox. They felt as though they were losing someone that was, at the same time, *still here*. One caregiver explained that "…she can still remember some things…she still has good days." These "good days" helped caregivers appreciate what remained, despite the fact that the care-recipients were quite impaired.

Discussion

Our study shows that these African American family caregivers lived in a state of paradox. While they tried to hang on to their care-recipients, they also realized that at some point, they would have to let go. And while they venerated what was still here, they were, at times, saddened by what was lost. This tension between *hanging on* and letting go, between recognizing what is *still here* but lost, may be explained by understanding the lens through which these caregivers view their lives and work. Heidegger asserted that humans live within their own “worlds” that are made of entities such as culture, language and time. The meaning and challenges the caregivers in our study experienced were shaped by their worlds: their history, family values, and faith—all nested within the present time. For these caregivers, ancestral African values, and the history of slavery and oppression shaped how they perceived their care-recipients’ and therefore, the dementia-related changes.

Looking back into their history, these caregivers recognized that their lives were shaped by oppression, both in slavery and subsequent oppressive laws and discrimination. The CAC (2014, February 21) advised that the caregivers’ need to *hang on* to their care-recipients was influenced by the caregivers’ social history which is based on ancestral African values of family cohesion and respect for the elders. These values were transported to the US with the slave trade and helped African American families develop and maintain kinship ties despite the trauma of separation during slavery (Laurie & Neimeyer, 2010; Pollard, 1981; Sudarkasa, 1997). The CAC (2014, February 21) added that the history of slavery informed the value of staying together:

> You could have the best, tight-knit family…and the master could come and say, ‘I’m taking this person.’ He’s trading them up and selling them. You had nothing to say about it, there’s nothing you could do about it. It just happened and it happened a lot. And so if you could keep somebody for any length of time you kept them.

The CAC (2014, January 10) and several of the caregivers felt that, even today, in the PNW, families felt the influence of ancestral slavery and oppression on their present-day caregiving experiences. Centuries later, the bonds among family members in this study were quite strong and the values of the primacy of the family, respect for elders (Haley et al., 1996) and the need to *hang on* was apparent. The dementia-related changes had limited meaning as long as separation was avoided and the family members could still spend time together.

Along with keeping care-recipients close, some of the caregivers did not consider long term care placement because they felt their family would be mistreated. This concern is grounded in the reality that skilled care for African Americans was dangerously subpar during the Jim Crow years: "…because we weren't allowed to have our loved ones in say 'care facilities' or hospitals and if you did have them in the hospital that would be a death sentence" (Community Advisory Committee, 2014, February 21). Of interest, caregivers for the more impaired care-recipients did entertain the idea of long term care placement, but they worried that the care-recipients would feel as they were being "thrown away."

Partly because of this history, these families focused on *hanging on* to their care-recipients with dementia. They recognized that they were gradually losing the personhood of their care-recipients, but a sense of loss did not permeate their lives. These findings vary somewhat from those discussed in the literature, in which loss is a common and important theme for caregivers for persons with dementia. This literature reveals that, for many caregivers, the dementia-associated losses mean that the care-recipients are “gone” (Sanders & Corley, 2003, p. 46; Shim et al., 2012, p. 225) because the care-recipients’ personalities had changed beyond recognition. Our study found that the caregivers did not think of the care-recipients as *gone*. For them, the word *gone* was equated with death. These caregivers did not deny the fact that their care-recipients were changing, rather the word *gone,* in their eyes, didn’t apply to their situation.

Because the caregivers did not think of their care-recipients as *gone,* the word *grief* wasn’t always relevant to them. Some caregivers stated clearly that they didn’t have a sense of grief about the changes in their care-recipients, but others were somewhat perplexed: “I don’t even know really what to call it. I don’t’ even know if it’s grief,” and “I don’t know if grief is the right word…” This finding is in contrast to the literature that identifies pre-death grief as an important caregiver reaction to dementia-related loss (Large & Slinger, 2013; Madsen & Birkelund, 2013; Shuter et al., 2013) and “an unavoidable component of caregiving” (Ziemba & Lynch-Sauer, 2005, p. 103). By way of explanation, the CAC suggested that some of the caregivers were grieving, but didn’t recognize the word as fitting with their experience. They also advised that *grieving* is something one does when a family member has died. These caregivers did not recognize their care-recipients as deceased or *gone.* In fact many reported that they felt blessed that they were still alive and active in the family.

Our study reveals that by focusing only on the losses associated with dementia and resulting grief, we may be missing an important aspect of how African American caregivers make meaning of dementia in a family member. While we did find evidence of burden and loss, it was important to the caregivers in our study that we understand that they still held their elder care-recipients in high regard, worked to keep them present, and hoped that they would, “God willing…live to 100.” For them, dementia was not “a complex, unknowable world of doom, ageing, and a fate worse than death,” (Zeilig, 2014, p. 262) but a part of an elder’s journey. Because it was framed as part of life, the sense of loss related to the dementia-related changes was overshadowed by the fact that the elder was still present and participating in the family unit.

These findings are similar to Ikels’ (2002) who found that dementia in Chinese elders was of limited significance. Instead, the elders were highly valued because they had “abundant life force” (p. 236) that allowed them to live long lives. In both the elder Chinese in Ikels’ (2002) study and the African American care-recipients in this one, the value of the person was determined not by his or her achievements in life, but by his status in the family—an elder worthy of respect (Shweder & Bourne, 1982).

Therefore, while burden and loss were acknowledged by the caregivers in our study, suffering did not suffuse their experiences (Farran & Keane-Hagerty, 1991). Instead, through *hanging on* to the care-recipients who were *still here*, caregivers talked of “moments of joy”, “blessings” and “at least I have her.” Losses were, in many cases, eclipsed by the caregivers’ ability to see what was still preserved of the care recipient’s valued personhood.

How these caregivers understood the dementia-related changes in their care-recipients seemed to be influenced by their faith. Many studies have found, as ours did, that faith is important to the African American caregiving experience (e.g., Farran, Graham, & Loukissa, 2000; Hamilton et al., 2013; Jones-Cannon & Davis, 2005). The caregivers in our study spoke in terms of God protecting and blessing their care-recipients with long life. Families spoke about how they saw the slow progression of dementia as a blessing because it meant the care-recipient could be with their families longer.

Sun et al. (2010) found participation in religious activities lowered caregiver burden in their sample of rural African American caregivers and, similarly, the caregivers in our study turned to their faith to help them manage their sense of burden. This faith may have had a positive effect on coping or, paradoxically, contributed to a sense of feeling “drained.” Merritt and McCallum (2013) found that African American caregivers who scored higher on a religious coping measure tended to have lower cortisol slope scores, indicating higher levels of stress. In our qualitative study, conclusions cannot be drawn with regard to burden, coping and faith. However, the fact that all of the caregivers talked about their faith and many talked about burden suggests that these two constructs are important in understanding these caregivers' experiences.

To summarize, we found that the dementia-related changes meant these caregivers felt a need to *hang on* to what was *still here*, while having to come to terms with burden and loss. Historical influences and embodied faith influenced their commitment to maintain the function and vitality of their care-recipients. Present day burden and loss, and concerns about future losses, shaped their experiences. This study shows that the meaning these caregivers gave to dementia-related changes were mixed and did not fit neatly fit into dichotomized pattern of completely positive or fully negative experiences. Health professionals working with African American caregivers must recognize and work within this paradox of *hanging on* to what is *still here*, despite the inevitable challenges and losses.

Implications

This study provides more information about how African American family caregivers understand and respond to dementia-related changes. We found that the caregivers in our study focused on the remaining capabilities, talents and personality traits of their care-recipients with dementia. Yet, they also had to contend with the fact that their work was challenging and at times, met with loss. As such, this study has implications for both clinical work and future research.

From a clinical perspective, our study offers ample material which health care providers can use to initiate conversations with family caregivers about their experiences. This is particularly important in light of the fact that race concordance between caregivers and health care providers is not always possible in the US. African Americans physicians make up only 5.8% of the total employed physicians in the US and African American nurses make up only 12% of all employed nurses (U.S. Department of Labor, U.S. Bureau of Labor Statistics, 2011). However, race concordance is not the most valued quality of these relationships for African Americans. Rather, attentive listening, shared decision making, and clinician sensitivity have been found to be more important for these individuals (K. L. Phillips, Chiriboga, & Jang, 2012; Saha et al., 2003). Thus our study provides information that can be used to foster productive, mutually satisfying relationships between caregivers, care-recipients, and their health care providers. This is particularly important in conversations that involve sensitive issues, such as long-term care placement and end-of-life conversations.

This study found that the history of slavery and oppression shaped these caregivers' approach to *hanging on* to their care-recipients who were *still here*. Similarly, this history has shaped how caregivers understood long term care. Some of the caregivers contemplated long term care as a future option, but for others, placement wasn't an ideal choice. Several caregivers were adamant that they would not place their family members in facilities because they were afraid for the safety of their care-recipients. Unfortunately, their concerns are still valid. Currently, African Americans in skilled nursing are more likely to live in facilities with deficiency ratings indicative of risk of immediate harm (Smith et al., 2007). Health care providers can use the findings from this study to sensitively discuss placement choices with caregivers. Health care providers need to recognize the dismal history of long term care quality with African Americans, but at the same time, help these caregivers advocate for the quality care they deserve.

Another implication is that our study findings can be used to facilitate end-of-life conversations with African American caregivers. African American values around end-of-life care can vary from that of Whites (Kwak & Haley, 2005). Our findings can add to health care providers' knowledge so that they can appreciate possible cultural differences. The caregivers in our study focused on *hanging on* to the care-recipient and this hints that they may have trouble letting go at the end of life. The literature indicates that African American caregivers are less prepared for the death of their care-recipients and more likely to experience prolonged grief after death when compared with White caregivers. Owen et al. (2001) found that African American caregivers, in comparison to White caregivers, were less likely to accept the care-recipient's death and more likely to perceive the death as a great loss. Hebert et al (2006) found that the African American caregivers in their study were "not at all" prepared for the death of their care-recipient, even though their dementia was considered in the moderate to severe stages. These authors found that not being prepared for death resulted in higher complicated grief scores, and higher anxiety and depression scores after death.

The caregivers in our study did entertain the idea that the care-recipients would die and several considered their reactions to the death. But in general, they tended to speak of death as an event far in the future, “at some point she was will go…” Thus, it may be tempting to interpret their focus on what remains as a form of denial, but these caregivers seemed to have a realistic appreciation of the changes. However, their focus on what was *still here* might interfere with their ability to prepare for an inevitable death in the future.

Health care providers can offer a valuable service to African American family caregivers by introducing prognosis discussions into the clinic visits and providing opportunities to talk about end-of-life concerns early in the dementia trajectory. Bass and Bowman (1991) found that these conversations prior to the death of a care-recipient are more helpful in assuaging post-death distress than post-death conversations.

The findings from this study also have implications for future research. As noted, these caregivers did feel some loss in the face of dementia-related changes, but the term “grief” as a response to this loss didn’t resonate with them. The methodological implication is that scales commonly used in measuring caregiver grief may not be valid for all African American caregivers. The Marwit Meuser Caregiver Grief Index (MMCGI) (Marwit & Meuser, 2002), the MMCGI Short Form (SF) (Marwit & Meuser, 2005), and the Anticipatory Grief Scale (Theut, Jordan, Ross, & Deutsch, 1991) have been used in many studies to understand the pre-death grief experience of caregivers for persons with dementia (e.g., Adams & Sanders, 2004; Ford, Linde, Gigliotti, & Kim, 2013; Sanders & Adams, 2005). However, only a small fraction of these studies included some African Americans (Holley & Mast, 2010; Ross & Dagley, 2009). Of concern, some items on these measures may not be meaningful for African American caregivers. For example, “I have this empty, sick feeling knowing that my loved one is ‘gone’” (Marwit & Meuser, 2002, p. 726) and “I feel detached from my relative” (Theut et al., 1991, p. 117) may not be valid with these caregivers. “I will be tied up with this for who knows how long” (Marwit & Meuser, 2005, p. 199) may not be an appropriate item for these descendants of enslavement. Future work is needed to validate these measures in the African American caregiver community (DeVellis, 2012b).

Strengths and Limitations

This study has several strengths and limitations. First, there are known cultural and racial differences between the investigators (White) and study participants (AA) which can be considered a strength of this study. For example, the participants may have felt comfortable revealing sensitive information to someone outside their close-knit community. The lead investigator assumed a naïve stance so that the caregivers could educate her about common norms, practices and beliefs (Adamson & Donovan, 2002; Ochieng, 2010). The majority of the caregivers in this study were passionate about their understanding of the AA history in the PNW and eager to instruct the investigator.

Alternatively, the cultural divide could have been a limitation to this study. The caregivers may not have felt comfortable talking about their feelings in-depth with a person of a different race (Adamson & Donovan, 2002). Nonetheless, the CAC (2014, January 12) explained that because the AA population is relatively small in the PNW (less than 4% of the total; U.S. Census Bureau, 2014), African Americans are used to doing business, going to school, and receiving health care with White members of the community. Therefore, they felt racial differences would not influence data quality.

Another potential limitation is that many of the care-recipients did not have a formal diagnosis of dementia. To ascertain whether a care-recipient had dementia we used the Alzheimer's Association's Criteria for All-cause Dementia (Alzheimer's Disease Dementia Workgroup, 2010). We depended solely on the caregivers' responses and thus, there may have been inaccuracies in their reports.

Finally, all but one of the caregivers in this study were women. It is possible that they may have embodied the *Superwoman* schema, in which AA women feel they have the obligation to be successful, strong caregivers in order to help their families thrive and to resist dependence on others (Woods-Giscombe, 2010). Viewing the findings from this perspective may have revealed alternative themes, such as how these women managed stress or how they understood their value and power within the family unit (hooks, 1990).

Conclusion

This study offers a fresh, in-depth look into the African American caregiving experience by examining the meanings these caregivers in the PNW ascribe to dementia-related changes. Through this work we are able to more fully appreciate how the historical backdrop of slavery and oppression shapes their understanding of their care-recipients with dementia. This is not to say that this history directly informs their comprehension of, or reactions, to dementia-related changes. Rather, it seems to subtly shape how they understand their experiences. The implications being that, in order to fully and effectively address the concerns of these caregivers (and any caregiver) one must consider the full complement of their “worlds”—the culture, language, history (and so forth) that defines who they--and we--- are (Leonard, 1994, p. 46).

Chapter 5

Introduction

This last chapter of this dissertation has two sections. The first presents the interpretation and discussion of the findings. Woven into this section is a review of the three manuscripts written for this dissertation along with consideration of theoretical and practical implications of the findings. The second section is a summary which concisely amalgamates the full dissertation. This section includes discussion of the strengths and weakness of the research, and makes suggestions for future work.

Interpretation and Discussion of Findings

The findings are based on 22 in-depth interviews with 11 African American caregivers for persons with dementia and four observation sessions. Analysis of the interviews, field notes, observation notes, and interviews with the Community Advisory Committee (CAC) revealed two important meanings of dementia-related changes for these caregivers in the Pacific Northwest (PNW). Broadly, the interviews were interpreted to mean that the dementia-related changes meant that the caregivers had to *hang on* to the care-recipients who were changed, but *still here*.

Hanging on. The caregivers in this study recognized that their care-recipients were changing due to the effects of dementia. With this recognition of change, the caregivers tended to *hang on* to their care-recipient's personhood by helping him or her remain independent, functional, and present. For some caregivers, there was a sense of loss and burden, but these were not dominant themes. As discussed in the findings manuscript “The Meanings African American Caregivers Ascribe to Dementia-Related changes: The Paradox of Hanging on to Loss” (Chapter 4), I found that caregivers placed high value on the fact that their care-recipients were still with them and still actively participating in family life. They respected their elder care-recipients and, for the most part, wanted the care-recipients to live as long as possible.

What was interesting was that it appeared that, through the interviews, many of these care-recipients had moderate to severe dementia. Behavioral symptoms of dementia included agitation, apathy and wandering. Some care-recipients were disinhibited, causing the caregivers to feel embarrassed by their behaviors. Memory loss and impaired executive function were common. None of the care-recipients lived alone or could prepare their own meals. All of them needed help with bathing and toileting. Word-finding problems, withdrawal, and forgetfulness limited communication. The observation sessions revealed that the care-recipients were more impaired than the caregivers revealed at the first interview. Three of the care-recipients were nonagenarians. Yet, the caregivers spoke of hoping the care-recipients could live for a long time (“Lord willing, she could live to be 100”) and most spoke of their care-recipients with affection and pride. They saw the fact the dementia was a slow process was a “blessing” which allowed them to “watch her grow old.”

These findings are in contrast with the literature that addresses the experiences of White caregivers. In Jones and Martinson’s classic work (1992) caregivers saw their care-recipients losing their personhood “inch by inch” and therefore the caregivers endured a “10-year funeral” (p. 174). More recently, other researchers have found that caregivers yearned for who their care-recipients once were, felt lonely, isolated, and wished for the death of their family members with dementia (Albinsson & Strang, 2003; Frank, 2008; Knutsen & Raholm, 2009; Sanders et al., 2008).

For the most part, caregivers in this study did not wish for the death of their care-recipients, nor did they speak of yearning for the person their care-recipient once was. Some considered that the care-recipient might die in the future but in general they focused on the present. The CAC (2014, February 21) advised the gratefulness for the very presence of the care-recipient may be informed by the history of enslavement and oppression of African Americans.

The ancestors of many African American caregivers were taken from Africa during the US slave trade. The values of family cohesion and respect for the elders were transported from Africa with them to the US. These values allowed African American families to maintain kinship ties despite the trauma of separation during slavery (Sudarkasa, 1997).

Centuries later, the bonds among family members in this study were quite strong and the values of the primacy of the family, respect for elders and the need to *hang on* was apparent. The dementia-related changes had limited meaning as long as separation was avoided and the family members could spend time together. The CAC (2014, February 21) instructed that the history of slavery informed the value of staying together:

> You could have the best, tight-knit family…and the master could come and say, 'I'm taking this person.' He's trading them up and selling them. You had nothing to say about it, there's nothing you could do about it. It just happened and it happened a lot. And so if you could keep somebody for any length of time you kept them.

The CAC (2014, February 21) felt that, even today, in the PNW, families viewed their caregiving experience through lens of ancestral slavery

Still Here. *Still here* was the second important theme found in this study. Because the care-recipients were considered "precious" and valuable to the families, the dementia-related changes were somewhat irrelevant. What was important was that the care-recipients were *still here*.

This finding varies somewhat from the current literature. Only a few papers discuss caregivers' continued appreciation for the care-recipient despite changes (Mazaheri et al., 2011; Paun, 2003). For the most part, the literature indicated that many caregivers thought of the care-recipients as "gone" even though they were still alive (Sanders & Corley, 2003, p. 46). This sense that they were *gone* was due to the fact that the care-recipients personalities had changed beyond recognition (Adams, 2006; Albinsson & Strang, 2003; Dupuis, 2002) and caregivers responded with pre-death grief.

Pre-death grief is defined as the emotional and physical responses to perceived dementia-related losses in a valued care-recipient. These responses are due to the psychological death of the care-recipient which is asynchronous with the physical death (Lindauer & A Harvath, 2014). The work of Sanders and others have described the pre-death grief experience and have identified it as an important component of dementia caregivers' experience (Sanders & Corley, 2003; Sanders et al., 2003; Sanders et al., 2008). They found that men, women, spouses and adult children experienced pre-death grief and that it was associated with depression (Sanders & Adams, 2005), guilt, yearning (Sanders et al., 2008) and desperation resulting in thoughts of caregiver murder and suicide (Sanders et al., 2003). Similarly, Ziemba (2005) identified pre-death grief as "an unavoidable component of caregiving" (p. 103).

In this study, because the care-recipients were *still here*, the word *grief* wasn't always relevant to the caregivers. These finding are in contrast to the literature that identifies pre-death grief as an important component of caregiving. The CAC (2014, February 21) suggested that some of the caregivers were experiencing grief, but didn't recognize the word as fitting with their experience.

In my study, I did find that for some caregivers, the dementia-related changes meant loss but none of them felt that their care-recipient was truly *gone*. Caregivers recognized that their care-recipients were losing cognitive function and that their personalities were changing. Caregivers missed meaningful conversations and social outings, such as going out to “have a beer at the bar, play poker…” or going fishing. They recognized that their care-recipients were “a little slower,” and “deteriorating,” but for the most part, their care-recipients were *still here* and the caregivers appeared grateful for this.

Despite the fact that many of the caregivers worked to *hang on* to their car-recipient and placed high value on their very presence, burden was noted in this study. The finding of burden, that it “wears me out sometimes,” was identified in most of the caregivers in our study. While I did not measure burden, these responses diverged somewhat with Pinquart and Sorensen’s (2005) comparative meta-analysis which found African American caregivers had lower levels of burden that the White caregivers. It is possible that the caregivers in our study had a strong commitment to the African American values of care, which may have influenced their psycho-social coping. Of interest, not many of the caregivers recognized long term care placement as an option to alleviate their burden. Instead these caregivers spoke of their faith as buffering their burden.

In this study all of the caregivers made some reference to their faith. This faith may have had a positive effect on coping or, alternatively contributed to a sense of feeling “drained.” Merritt and Mc Callum (2013) found that African American caregivers who scored higher on a religious coping measure tended to have lower cortisol slope scores, indicating higher levels of stress. In this qualitative study, conclusions cannot be drawn with regard to burden, stress and coping. However, the fact that all of the caregivers talked about their faith and many talked about burden suggests that these constructs are important in understanding these caregivers’ experiences.

Since the mid-1700s, the Black church has sustained the faith and of African Americans (Reist, Alexander, Smith, & Cropsey, 2008; Turner & Bagley, 2000). Many of the caregivers in this study found sustenance in their faith, church attendance and reading the Bible. The CAC explained that, in the Bible, miracles happened that kept elders alive for hundreds of years. The belief system of many African Americans rests on the teachings of the Bible in that they valued longevity and hoped for miracles to keep family members alive even when they were quite old (Community Advisory Committee, 2014, January 12). Shades of this belief system were found in the caregivers in this study in that some of them felt that divine intervention kept their elders safe and helped them live a long life. Many of the caregivers in this study owned Bibles, cited versus from the Bible had had the Book in their houses. The

CAC (2014, January 12) explained: "…we believe in life…we believe in hope and we believe in the *Bible*—we truly believe all that."

In summary, the caregivers in this study venerated their elder care-recipients and, with the decremental changes associated with dementia, they worked to *hang on* to the capabilities and personalities of their care-recipients. They felt as though their care-recipients were *still here* despite substantial functional decline. These themes appeared to be influenced by the values of Africans brought over to the US during the slave trade. Faith and Biblical teachings shaped helped the caregivers understand the changes as somewhat irrelevant as long as the care-recipients could live long lives. The implications of these findings are discussed next.

Implications

I have come to understand that the focus of my study, the meaning of dementia-related changes, influences the meaning of caregiving. Hence, the study findings and the resulting theoretical, methodological and clinical implications are discussed by considering how the findings influence the African American caregiving experience.

Theoretical Implications. There were three important questions that influenced the development of this study: (a) how are dementia-related changes understood and discussed in the extant literature, (b) is the theory of ambiguous loss relevant to this study and (c) how is pre-death grief defined?

How are dementia-related changes discussed in the literature? First, in preparing for this study, I was interested in the literature that addressed how caregivers perceived the changes they saw in their family members with dementia. Much of the work on the on this subject focuses on loss and the emotional responses to this loss. Some literature addressed alternative meanings ascribed to the dementia-related changes (e.g., stigma), but this was limited. I prepared a manuscript to synthesize the qualitative literature on this topic: "The Meanings Caregivers Ascribe to Dementia-related Changes in Care-Recipients: A Meta-Ethnography" (see Chapter 2).

The syntheses revealed that, broadly, dementia-related changes have both negative and positive connotations for caregivers. My interpretation was that the meanings of these changes varied among caregivers, depending on a care-recipient's premorbid personality, image, and functional status. The meanings caregivers gave to the dementia-related changes were shaped by whether or not the premorbid personality was concordant or discordant with the care-recipient's current personality (L. Phillips & Rempusheski, 1986; Walters et al., 2010). A matrix was developed to demonstrate how pre-morbid personalities shape dementia-related meaning (Table 2.5).

My own study found two new categories of meaning. First, I found that the African American caregivers in this study perceived their care-recipients as changing with dementia progression. Because of this, the caregivers worked to maintain the care-recipients' current abilities and status in the family. Thus the dementia-related changes meant the caregivers had to *hang-on* to the remaining function and personhood of the care-recipients. Second, the dementia-related changes meant cognitive and functional decline and loss, but the caregivers appreciated the fact that the care-recipients were *still here* -- still valuable family members that deserved respect.

In my study, the majority of the caregivers fell into the “positive concordant” and “positive discordant” groups of the Matrix of Meanings of Dementia-related Changes (Table 2.5). The discordant aspect of the meanings for them was that they felt as though they were gradually losing their care-recipient’s personhood and this resulted in sadness. In both groups, the person with dementia was revered and considered valuable members of the families.

From another angle, the meaning of dementia-related changes could be considered in relation to Farran and Keane-Hagerty’s (1991) interactive model for finding meaning through caregiving (IMFMC). This model suggests that caregivers find meaning in caregiving through a process that rests on a foundation of values, caregiving stages, and responses to caregiving. The meanings identified in this study could be incorporated into an updated IMFMC model. Farran and Keane-Hagerty’s (1991) model is important because it recognizes that social history and personal values shape the caregiving experience. It seems slightly outdated, however, because it posits that caregiving is “an almost continual process of suffering” (p. 232). The focus on suffering limits incorporation of findings such as mine that indicate that the dementia-related changes have positive meaning.

My work extends Phillips and Rempusheski's (1986) and Farran and Keane-Hagerty's (1991) by considering how caregivers respond to dementia-related changes when the changes are perceived in a more positive light. This current study can be combined with their work of those and others (e.g., Henderson & Henderson, 2002; Mazaheri et al., 2011) to craft a middle-range, practical theory to assist nurses in helping caregivers adapt to their role (Chinn & Kramer, 2011b). Nursing theory that focuses on positive perceptions of dementia-related changes could remove some of the fear and stigma the word "dementia" brings to families (Zeilig, 2014). This type of theory could encourage development of effective interventions that fosters adaptive coping for African American (and other) caregivers.

Is the theory of ambiguous loss relevant to this study? The second theoretical challenge involved understanding how the theory of ambiguous loss fit with my study. Prior to study initiation, I considered that the theory of ambiguous loss might be meaningful to this work. This theory posits that the uncertain physical or psychological status of a loved one can be distressing to him or her and can contribute to the pre-death grief of family caregivers for persons with dementia (Boss et al., 1988). Some of the caregivers in my study spoke in terms of experiencing ambiguous loss ("She's my mom but she's not my mom"), but for the most part, most focused on the unambiguous fact that their care-recipient was *still here*. Instead of mourning the decremental losses, these caregivers focused on *hanging on* to the elder they still had.

It may be that ambiguous loss a complex experience and may fit with some caregivers, but not others (Boss, 2007). It is also possible that the history of separation and oppression influenced these caregivers' definition of "loss" and, as the CAC (2014, February 21) explained, "…if you could keep somebody for any length of time you kept them."

The theoretical implication here is that a study that focuses only on ambiguous loss, such as Dupuis's (2002) may be illuminating. Dupuis (2002) identified three phases of loss for daughters and sons of persons with dementia: anticipatory loss, progressive loss, and acknowledged loss. A study such as this that focuses on the African American experience would help determine if ambiguous loss is relevant in this community and if so, how. Alternatively, a secondary analysis of the data in my study could hone in on the cases in which ambiguous loss was evident. By delving more deeply into this data, the nuanced meanings may become more apparent. Either way, it appears that this theory has potential to be meaningful for African American caregivers, but the interviews of the 11 caregivers provided only a glimpse of its relevance.

How is pre-death grief defined? The last theoretical challenge was how to define *pre-death grief*. The literature revealed that caregivers for persons with dementia experienced a variety of emotions, including pre-death grief. Going into the study, I guessed that there might be caregiver testaments of this pre-death grief. However, no definition of the concept was identified in the literature. Therefore I examined the literature to identify the boundaries of this concept and reported this in the manuscript, “Pre-death Grief in the Context of Dementia Caregiving: A Concept Analysis.” This manuscript is published in the *Journal of Advanced Nursing* (Lindauer & A Harvath, 2014).

In this manuscript I provided a definition of the concept and contrasted it with chronic sorrow and anticipatory grief. I identified the need for a middle-range, situation specific theory of pre-death grief. Situation-specific theories focus on the needs of specific populations and recognize the interaction between culture, experience, and knowledge (Benner, 1985; Im & Meleis, 1999). These theories are designed to be useful to nurses in the practice environment (Chinn & Kramer, 2011b). I recognized that a situation-specific theory of pre-death grief could be used to inform nursing of the potential outcomes of dementia-caregiving.

However, pre-death grief was not a prominent finding in my study. The CAC (2014, February 21) suggested that some of the caregivers were experiencing grief, but didn’t recognize the word as fitting with their experience. They advised that *grief* is something one does when a family member has died. These caregivers did not recognize their care-recipients as *gone* and in fact felt blessed that they were still alive and active in the family. More work is needed to comprehend the full potential of pre-death grief as a middle-range, situation-specific theory.

From a methodological perspective, the fact that the concepts of loss and pre-death grief did not ring true for many of the caregivers in this study suggests that scales commonly used to measure pre-death grief may not be valid for all African American caregivers. The Marwit Meuser Caregiver Grief Index (MMCGI) (Marwit & Meuser, 2002), the MMCGI Short Form (SF) (Marwit & Meuser, 2005), and the Anticipatory Grief Scale (Theut et al., 1991) are measures that have been used in many studies to understand the pre-death grief experience of caregivers for persons with dementia (e.g., Adams & Sanders, 2004; Ford et al., 2013; Sanders & Adams, 2005). However, only a small fraction of these studies included some African Americans (Diwan et al., 2009; Holley & Mast, 2009; Holley & Mast, 2010; Ross & Dagley, 2009). Of concern, some items on these measures may not resonate with African American caregivers. For example, “I have this empty, sick feeling knowing that my loved one is ‘gone’” (Marwit & Meuser, 2002, p. 762) and “I feel detached from my relative” (Theut et al., 1991, p. 117) may not be valid with these caregivers. “I will be tied up with this for who knows how long” (Marwit & Meuser, 2005, p. 199) may not be an appropriate item for these ancestors of enslavement.

Clinical Implications. This study provides more information about how African American family caregivers understand and respond to dementia-related changes and thus the findings have clinical implications. First, this information can be used to inform health care providers about the African American caregiver experience in the PNW so that they can provide culturally-sensitive care for both the caregivers and care-recipients. Second, African American caregivers tend to avoid use of long term care for their care-recipients, but this trend is beginning to reverse (Feng et al., 2011). Finally, this study provides some insight as to why African American caregivers have worse mental health outcomes after the death of their family member than White caregivers. These implications are discussed next.

Oregon House Bill 2611 directs health care professionals to improve their understanding of the diverse needs of families across cultures (Keny-Guyer et al., 2013). This study directly addresses this call by providing local, rich data that can help PNW health care providers work with African American caregivers in an enlightened and thoughtful manner. Given that African Americans nurses make up only 12% of all employed nurses in the US (and African American physicians make up 5.8% of the total employed physicians) (U.S. Department of Labor, U.S. Bureau of Labor Statistics, 2011) race concordance between patients and providers is not always possible. However, Phillips (2012) found that race concordance was not a significant predictor of patient satisfaction with health care. Rather, higher levels of clinician sensitivity, such as understanding the background and values of a patient, predicted patient satisfaction. While the literature on how satisfaction with health care influences African American caregiver health could not be found, a link between quality of care and morbidity has been identified (Shadmi et al., 2006). Intuitively, culturally sensitive care could lend to higher care quality for these caregivers whose mortality risk is higher than White caregivers (Schulz & Beach, 1999). Providers' knowledge of local history and racism in this part of the US can go a long way to convey a message of interest and understanding for the African American caregivers in the PNW.

This study found that the history of slavery and oppression shaped these caregivers' approach to *hanging on* to their care-recipients. Similarly, this history has shaped how caregivers understood long term care. A few caregivers contemplated long term care as a future option, but for the most part, placement wasn't considered in these families. Those that did consider placement appeared to experience a higher level of burden than the others. One caregiver's care-recipient had entrenched hallucinations that made day-to-day living complicated, while another care-recipient had substantial problems with urinary incontinence. Neither of these caregivers was committed to the idea of placement, but it was clear that they considered it a viable option. This suggests that the gradual reversal of placement trends may be due to increasing burden for caregivers.

Several caregivers were adamant that they would not place their family members because they were afraid for the safety of their care-recipients. This reflects the CAC's comments that African Americans still perceive skilled care a risky option. This concern is grounded in the reality that skilled care for African Americans was dangerously subpar during the Jim Crow years: "…because we weren't allowed to have our loved ones in say 'care facilities' or hospitals and if you did have them in the hospital that would be a death sentence" (Community Advisory Committee, 2014, February 21). Unfortunately, their concerns are still valid. Despite Medicare reform in 1967, nursing home desegregation was largely ignored. Disparities in quality of skilled care are still seen today. African Americas in skilled nursing are more likely to live in facilities with deficiency ratings indicating risk of immediate harm (Smith et al., 2007).

My meta-ethnography identified that some caregivers may not be in the best of situations to provide in-home care and placement should be a considered a safe option. Health care providers in the PNW can use the findings from this study to sensitively discuss placement choices with caregivers. Health care providers need to recognize the dismal history of long term care use with African Americans, but at the same time, help these caregivers advocate for the quality care they deserve.

The final implication is that African American caregivers may benefit from discussions about the prognosis of dementia. The caregivers in our study focused on *hanging on* to the care-recipient and this hints that they may have trouble letting go at the end of life. The literature indicates that African American caregivers are less prepared for the death of their care-recipients and more likely to experience prolonged grief. Owen et al. (2001) found that African American caregivers were less likely to accept the care-recipient's death and more likely to perceive the death as a great loss. Hebert et al (2006) found that the African American caregivers in their study were "not at all" prepared for the death of their care-recipient (p. 687). These authors found that not being prepared for death resulted in higher complicated grief scores, and higher anxiety and depression scores.

The caregivers in our study did entertain the idea that the care-recipients would die and several considered their reactions to the death. But in general, they tended to speak of death as an event far in the future, "at some point she was will go…" They tended to focus on the present situation and enjoyed spending time together. Clinicians can provide a valuable service to African American family caregivers by introducing prognosis discussions into the clinic visits and providing opportunities to talk about end-of-life concerns. Bass and Bowman (1991) found that these conversations prior to the death of a care-recipient are more helpful in assuaging post-death distress than post-death conversations.

Summary

This summary section provides an overview of the study, findings and implications. The purpose of this study was to gain a deeper understanding of how African American caregivers for persons with dementia appraise their situations. Specifically, the aims were to (a) understand the meanings African American family caregivers ascribe to the dementia-related changes in their care-recipients with ADRD, and (b) explore African American family caregivers' emotional responses to these dementia-related changes in persons with ADRD.

Researchers have found that, for many caregivers, the dementia-related changes mean loss and the caregivers typically respond with pre-death grief (Lindauer & A Harvath, 2014). Pre-death grief is associated with caregiver burden (Holley & Mast, 2009), depression (Sanders & Adams, 2005), impaired physical health and consideration of long term care placement (Walker & Pomeroy, 1997). These findings come from studies in which most of the subjects were White. The studies that address the meaning of dementia-related changes across cultures are scare. Some insight is provided from a study of Iranian caregivers (Mazaheri et al., 2011) and one Native American family (Henderson & Henderson, 2002). These studies found that the dementia-related changes can have positive meanings (e.g., special powers). No studies exist that specifically address the meaning African American caregivers ascribe to dementia-related changes. While these caregivers are included in some studies that address loss (Diwan et al., 2009; Owen et al., 2001; Sterritt & Pokorny, 1998) , in general, we know very little about their experiences.

Through use of the method of interpretive phenomenology (IP), I sought to understand the African American experience. IP is grounded in the work of Heidegger (1962) who contended that human beings and the world they live in are inextricably linked. Each person is influenced by, and influences his world. For Heidegger (1962), *world* is a construct encompassing culture, language, community, and history. This world exists in time: past, present and future. Therefore, what happens today is formed by what happened in the past and what will happen in the future. Because we are all part of each other's worlds, an important starting point in the process is recognizing how the investigator's background affects the research process. For example, while engaged in this study I considered how my background as a gerontological nurse practitioner and daughter of a person with dementia influenced the study findings. Instead of trying to ignore my background, I recognized my unique position and used my experiences to understand the caregivers' (Benner, 1994).

Because I am a White woman, two African American women from the community agreed to function as my advisors (the Community Advisory Committee, CAC). The CAC assisted with recruitment, provided valuable background information, and discussed interview themes with me and my committee Chair. This team consisted of two older African American women from the community. Both women grew up in the African American neighborhood in Portland. Key informants indicated that they would be ideal CAC members because they are well-known, highly respected members of the community. In order to improve my understanding of the African American community I started meeting with the CAC 18 months prior to study initiation. These early meetings allowed the CAC to educate me about the African American community, appropriate comportment and study design. An important question early in study design was which term ("Black" or "African American") was best to use for the study. They advised that the older caregivers would prefer "African American" and thus, this term was used throughout the study and in this dissertation.

This study involved interviewing 11 caregivers twice and observing four caregivers once. The interviews lasted 35 to 90 minutes and focused on understanding the taken-for-granted meanings the caregivers ascribed to the dementia-related changes. In IP, it is assumed that the meanings are not obvious to the caregivers and questions about daily life and past experiences will unveil these meanings (Benner, 1994). Therefore, the interviews started with asking the caregivers to tell a story about what the care-recipient was like prior to the dementing illness. Questions were modified as needed to grasp how the caregivers perceived their care-recipients in the past and in the future.

The analytic process involved listening to the interviews, writing summaries, and then discussing the summaries with the dissertation committee, the caregivers, and the CAC. The summaries were then re-written to include new insights. This writing process allowed for the investigator to interpret the findings and then test the interpretations with the caregivers and committees.

Through the interviews and interpretive process, I identified two important themes. First, for these caregivers, the dementia-related changes meant their care-recipient was losing some function and the caregivers had to work to maintain the care-recipient's current abilities and importance in the family. This theme was entitled, *hanging on*. Second, the dementia-related changes meant cognitive and functional decline and loss, but the caregivers appreciated the fact that the care-recipients still deserved respect and compassion. This theme was labeled *still here*.

For the most part, the caregivers appeared to be grateful for the presence of the care-recipients and did not find the changes too distressing. They focused instead on *hanging on* to the care-recipients' capabilities. This involved health promotion activities and socialization with community members. For some of the caregivers, part of *hanging on* was coping with burden. The sense of burden caused some caregivers to feel overwhelmed, tired, and as though they were aging themselves. It appeared that cultural values of primacy of the family and veneration of elders, combined with a strong religious faith, buffered some of the caregivers' burden.

The second important theme was *still here*. The caregivers appreciated the fact that their care-recipients were changing, but instead of mourning their losses, they were grateful for the remaining personhood of their care-recipients. These caregivers were not immune, however to the emotions that come with the recognition of loss and they responded with both acceptance and pre-death grief. While they recognized their care-recipients had changed they did not feel, as caregivers in the literature reported, that their care-recipients were *gone*. These caregivers felt paradoxically saddened by the losses but "blessed" by the opportunity to be with their care-recipients as they grew old.

These findings are in contrast with those in the literature. Much of the current literature reports that caregivers feel as though their care-recipients are "gone" (Sanders et al., 2003, p. 46) and thus responded with pre-death grief. While a few authors identified positive meanings (e.g., Mazaheri et al., 2011; Paun, 2003) the majority reported that the caregivers were bereft due to the changes they witnessed. This study reveals that these African American caregivers responded in ways that were quite different than their White counterparts. The meanings of *hanging on* and *still here* indicate a level of acceptance not typically seen in the literature.

The CAC and several caregivers advised that these themes are informed by the history of slavery and oppression in the US. While the Emancipation Proclamation seems to be a remote event, to these caregivers this oppression is an ever-present reminder to “hang on to each other.”

While the findings have limited generalizability, they do provide information that can inform health care providers in Oregon. Oregon House Bill 2611 directs health care professionals to improve their understanding of the diverse needs of families across cultures (Keny-Guyer et al., 2013). This study directly addresses this call by providing local, rich data that can help Oregon health care providers work with African American caregivers in an enlightened and thoughtful manner.

As with any study, limitations are noted in this one. First, I am not a member of the African American community in Portland. This may have limited the depth of data provided by the caregivers. Second, I relied solely on caregiver input to ascertain if their care-recipient had dementia. Despite the evidence that they provided, it is possible that errors in dementia identification were made.

Finally, the majority of the caregivers in this study were women. It is possible that they may have embodied the *Superwoman* schema, in which AA women feel an obligation to be successful, strong caregivers in order to help their families thrive and to resist dependence on others (Woods-Giscombe, 2010). Viewing the findings from this perspective may have revealed alternative themes, such as how these women managed stress or how they understood their value and power within the family unit (hooks, 1990).

Conclusion

This study offers a fresh, in-depth look into the African American caregiving experience by examining the meanings these caregivers in the PNW ascribe to dementia-related changes. Through this work we are able to more fully appreciate how the historical backdrop shapes their understanding of their care-recipients with dementia. This is not to say that the history of oppression and slavery directly informs their comprehension of, or reactions, to dementia-related changes. Rather, this history seems to subtly shape how these caregivers understand their experiences. The implications being that, in order to fully and effectively address the concerns of these caregivers (and any caregiver) one must consider the full complement of their “worlds”—the culture, language, history (and so forth) that defines who they are (Leonard, 1994, p. 46). Over a century ago, the revered African American W.E.B. Du Bois (1898) wrote: “One cannot study the Negro in freedom and come to general conclusions about his destiny without knowing his history in Slavery” (p. 12). Even today, over 150 years after the signing of the Emancipation Proclamation, slavery implicitly shaped the beliefs and practices in these PNW families. Understanding this background helps shine a light on the meaning these caregivers attribute to dementia-related changes and the emotional responses to these changes.

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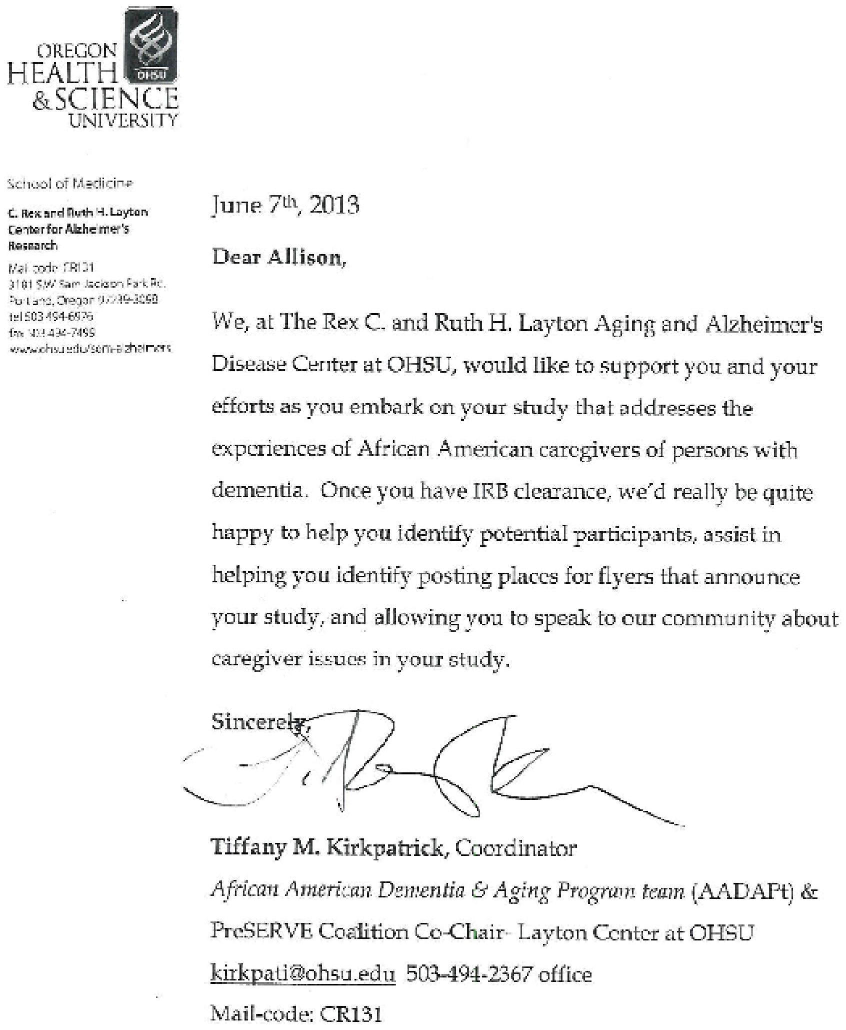
Appendix A

Letters of Support



OREGON
HEALTH
& SCIENCE
UNIVERSITY

School of Medicine

C. Rex and Ruth H. Layton
Center for Alzheimer's
Research

Mail code: CR131
3181 S.W. Sam Jackson Park Rd.
Portland, Oregon 97239-3098
tel 503 494-6976
fax 503 494-7499
www.ohsu.edu/som-alzheimers

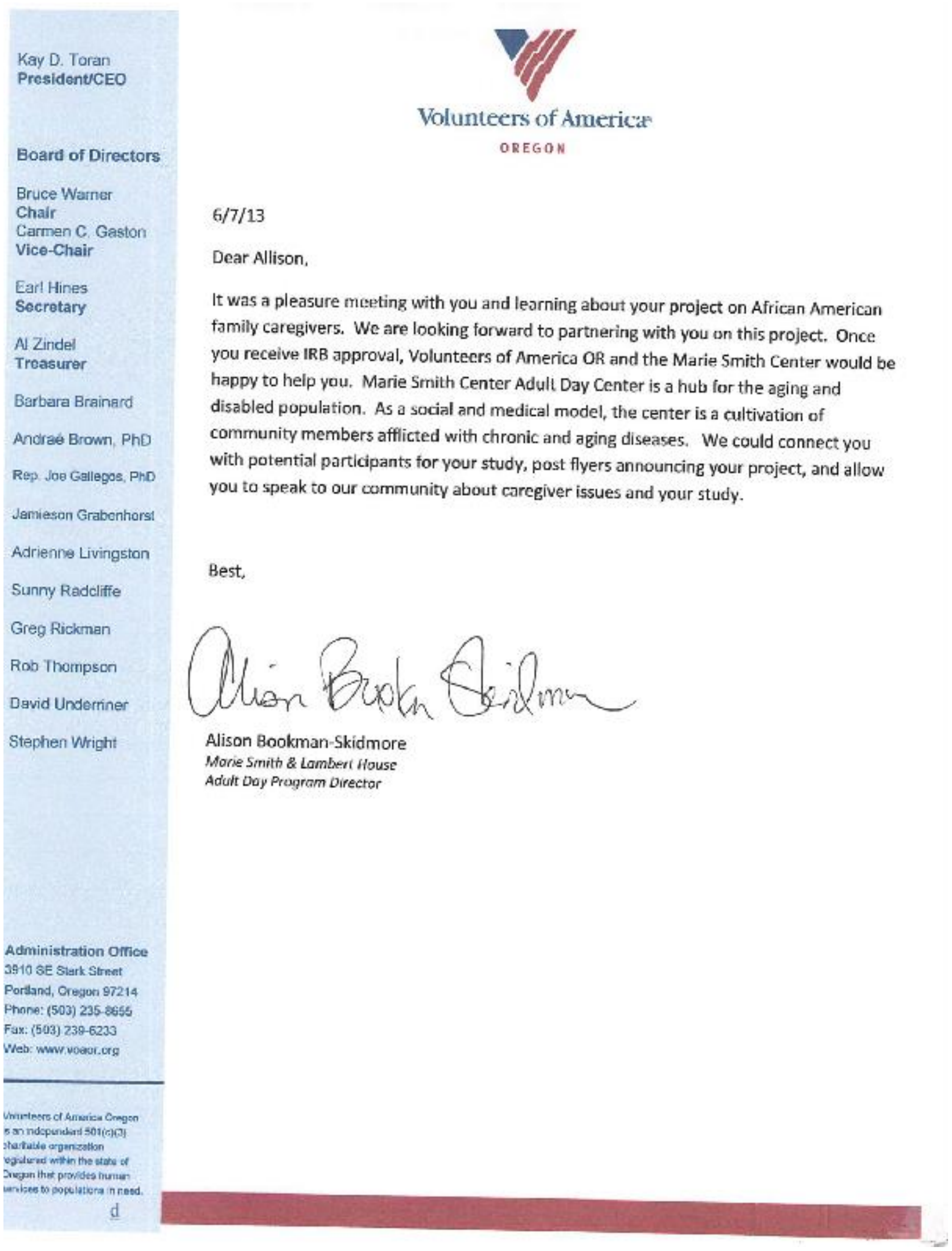
June 7th, 2013

Dear Allison,

We, at The Rex C. and Ruth H. Layton Aging and Alzheimer's Disease Center at OHSU, would like to support you and your efforts as you embark on your study that addresses the experiences of African American caregivers of persons with dementia. Once you have IRB clearance, we'd really be quite happy to help you identify potential participants, assist in helping you identify posting places for flyers that announce your study, and allowing you to speak to our community about caregiver issues in your study.

Sincerely,

Tiffany M. Kirkpatrick, Coordinator
African American Dementia & Aging Program team (AADAPt) &
PreSERVE Coalition Co-Chair- Layton Center at OHSU
kirkpati@ohsu.edu 503-494-2367 office
Mail-code: CR131



Volunteers of America
OREGON

6/7/13

Dear Allison,

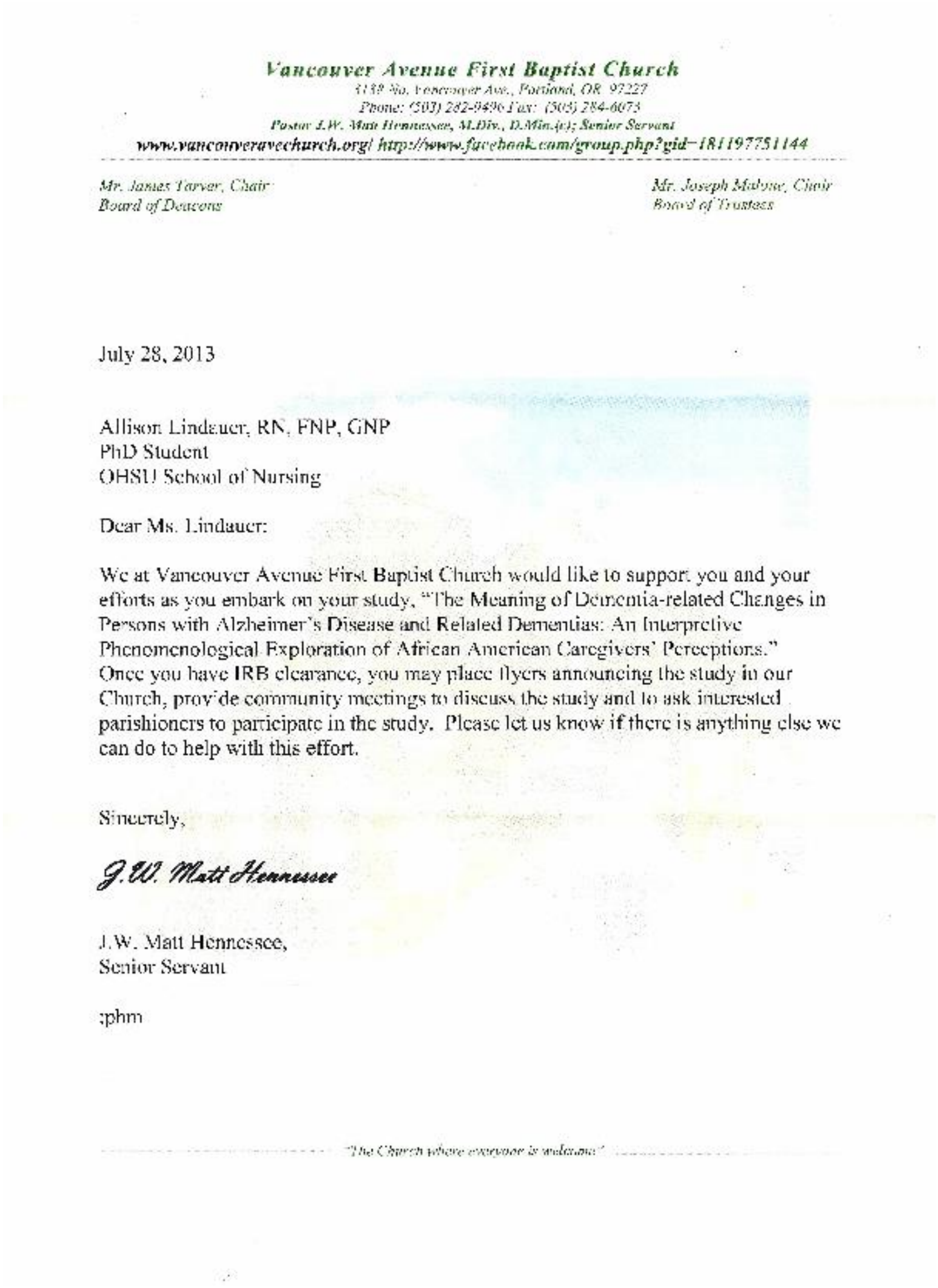
It was a pleasure meeting with you and learning about your project on African American family caregivers. We are looking forward to partnering with you on this project. Once you receive IRB approval, Volunteers of America OR and the Marie Smith Center would be happy to help you. Marie Smith Center Adult Day Center is a hub for the aging and disabled population. As a social and medical model, the center is a cultivation of community members afflicted with chronic and aging diseases. We could connect you with potential participants for your study, post flyers announcing your project, and allow you to speak to our community about caregiver issues and your study.

Best,

Alison Bookman-Skidmore
Marie Smith & Lambert House
Adult Day Program Director

Administration Office
3910 SE Stark Street
Portland, Oregon 97214
Phone: (503) 235-8655
Fax: (503) 239-6233
Web: www.voaor.org

d



Vancouver Avenue First Baptist Church
3138 No. Vancouver Ave., Portland, OR 97227
Phone: (503) 282-9496 Fax: (503) 284-6073
Pastor J.W. Matt Hennessee, M.Div., D.Min.(c); Senior Servant
www.vancouveravechurch.org/ http://www.facebook.com/group.php?gid=181197751144

Mr. James Tarver, Chair
Board of Deacons

Mr. Joseph Malone, Chair
Board of Trustees

July 28, 2013

Allison Lindauer, RN, FNP, GNP
PhD Student
OHSU School of Nursing

Dear Ms. Lindauer:

We at Vancouver Avenue First Baptist Church would like to support you and your efforts as you embark on your study, "The Meaning of Dementia-related Changes in Persons with Alzheimer's Disease and Related Dementias: An Interpretive Phenomenological Exploration of African American Caregivers' Perceptions." Once you have IRB clearance, you may place flyers announcing the study in our Church, provide community meetings to discuss the study and to ask interested parishioners to participate in the study. Please let us know if there is anything else we can do to help with this effort.

Sincerely,

J.W. Matt Hennessee

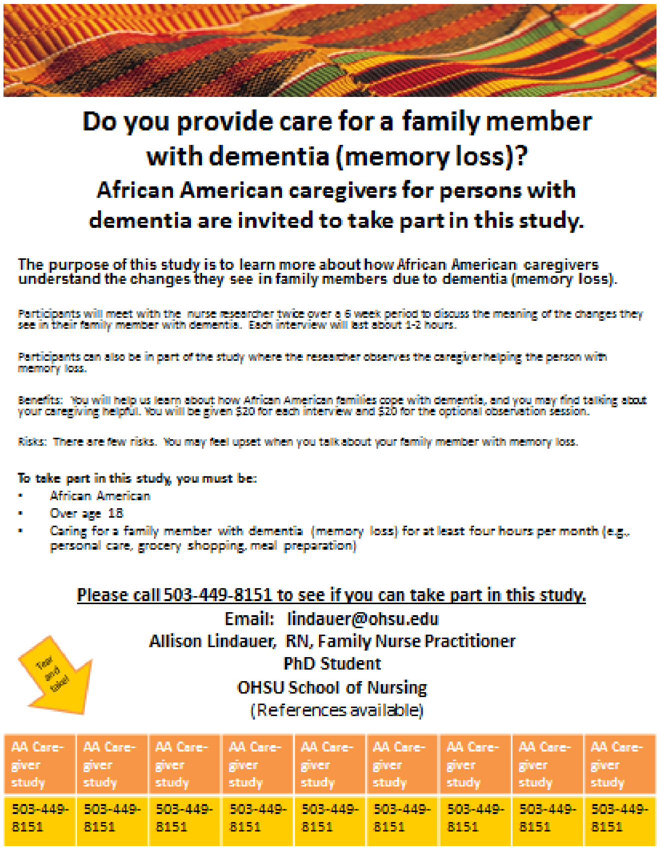
J.W. Matt Hennessee,
Senior Servant

:phm

"The Church where everyone is welcome"

Appendix B

Study Flyer



Do you provide care for a family member with dementia (memory loss)?

African American caregivers for persons with dementia are invited to take part in this study.

The purpose of this study is to learn more about how African American caregivers understand the changes they see in family members due to dementia (memory loss).

Participants will meet with the nurse researcher twice over a 6 week period to discuss the meaning of the changes they see in their family member with dementia. Each interview will last about 1-2 hours.

Participants can also be in part of the study where the researcher observes the caregiver helping the person with memory loss.

Benefits: You will help us learn about how African American families cope with dementia, and you may find talking about your caregiving helpful. You will be given $20 for each interview and $20 for the optional observation session.

Risks: There are few risks. You may feel upset when you talk about your family member with memory loss.

To take part in this study, you must be:

- African American
- Over age 18
- Caring for a family member with dementia (memory loss) for at least four hours per month (e.g., personal care, grocery shopping, meal preparation)

Please call 503-449-8151 to see if you can take part in this study.

Email: lindauer@ohsu.edu

Allison Lindauer, RN, Family Nurse Practitioner

PhD Student

OHSU School of Nursing

(References available)

AA Care-giver study	AA Care-giver study	AA Care-giver study	AA Care-giver study	AA Care-giver study	AA Care-giver study	AA Care-giver study	AA Care-giver study	AA Care-giver study
503-449-8151	503-449-8151	503-449-8151	503-449-8151	503-449-8151	503-449-8151	503-449-8151	503-449-8151	503-449-8151

Appendix C

Roles and Responsibilities of Community Advisory Committee(CAC)

Member	Tasks	Description of Responsibilities
Lead Investigator	Study development, execution, oversight.	• Responsible for study design, execution. • Seek guidance from advisors on study design, execution and culturally-appropriate research strategies. • Instruct advisors on responsible and ethical conduct of research. • Provide instruction and guidance on expectations, tasks. • Respond to questions, needs in timely manner. • Include advisors in presentations, research dissemination as deemed appropriate by research team. • Revise Advisors' Responsibilities as needed.
Community Advisors	Engage in Responsible Conduct of Research	• Complete OHSU's required training: Responsible Conduct of Research, Conflict of Interest. • Report concerns or issues
Community Advisors	Advise Lead Investigator	• Advise on study design and development • Discuss study; make recommendations for culturally-appropriate wording, interactions. • Critique interview questions, style, provide supportive feedback. • Advise on revisions of Advisors' responsibilities (if needed) throughout study course.
Community Advisors	Assist with recruitment	• Identify potential participants and refer to investigator • Explain study purpose; give study flyer to potential participant with contact information. • Ask for permission for investigator to contact her.

Roles, Cont.

Community Advisors	Provide information to participants	• Describe lead investigator's background, work in community, reputation. • Confirm that potential participant has all contact information. • Ask if potential participant has questions/concerns.
Community Advisors	Assist in data analysis	• Review de-identified transcripts and interpretive summaries. • Provide insight into meaning of interviews. • Advise on cultural content.
Dissertation Committee Members	Advise on CAC's Roles and Responsibilities	• Meet community advisors. • Advise lead investigator and advisors on research issues or concerns that may arise.

Appendix D

Screening Process for Potential Participants

Step	Task
1 Identification	Potential participant is identified through community contacts, CAC, flyer, or word of mouth. She calls or emails lead investigator or gives permission for investigator to contact her.
2 Contact	Lead investigator contacts potential participant, explains study and asks if potential participant is interested • Not interested: Thank her and ask if she knows of others who might be interested. (Screening ends). • Unsure: Answer any questions and offer CAC phone numbers for reference and information. • Interested: Answers questions, reviews criteria.
3 Screening, potential participant	Does potential participant meet inclusion criteria? • Identifies as African American • Family caregiver for person with dementia for at least 1 month • Provides 4 hours or more of care per month • Over age 18 • Speaks English • Lives within 50 miles of lead investigator
4 Screening, confirm dementia in care-recipient	Cognitive and behavior changes which: • Interfere with work or social activities • Represent a decline from previous functioning. • Are not explained by delirium or major psychotic disorder. • Impaired ability to retain new information Plus at least 2 of the following: • impaired reasoning • impaired visual-spatial skills • impaired language skills • personality change
5 Invitation	If eligible, invite potential participant to enter study
6 Arrange visit	Arrange visit to clarify study, answer questions, obtain consent and start interviews.

Appendix E

Consent Forms

OREGON
HEALTH & SCIENCE
UNIVERSITY

IRB#: 9777

Research Consent Summary

You are being asked to join a research study. You do not have to join the study. Even if you decide to join now, you can change your mind later.

One part of this study is optional. You may participate in the main study without participating in the optional part.

1. The purpose of this study is to learn more about how African American caregivers understand the changes they see in family members due to dementia (memory loss).
2. We want to learn
    a. About the meaning African American caregivers give to the dementia-related changes they see in their family members and
    b. What the emotional responses are to these changes
3. If you join the study, you will be interviewed two times over a 6 week period.
4. There is a small risk of breach of confidentiality. Talking about the changes in your family member may be stressful for you.
5. The optional part of the study includes participating in a session in which you will be observed caring for your family member once in the 6 week period.

OREGON
HEALTH&SCIENCE
UNIVERSITY

IRB#: 9777

Research Consent and Authorization Form

TITLE: The Meaning of Dementia-related Changes in Persons with ADRD: An Interpretive Phenomenological Exploration of African American Caregivers' Perceptions

PRINCIPAL INVESTIGATOR:	Theresa Harvath, PhD, RN, CNS (503) 494-3855
CO-INVESTIGATOR:	Allison Lindauer, RN, FNP (503) 449-8151

PURPOSE:
You have been invited to be in this research study because you are an African American family caregiver for a person with dementia (memory loss). The purpose of this study is to explore the meaning African American caregivers give to the changes in their family members with dementia (memory loss) and the feelings caregivers have about these changes.

You will be interviewed twice: Once at the beginning of the study and then about 2-6 weeks after the first interview. The interviews will take about 1 to 2 hours to complete.

10-30 participants will take part in this study.

PROCEDURES:
Participants will be asked to discuss what they think the changes they see in their family members (due to memory loss) mean and their feelings about these changes.

You will be asked to provide minimal information about yourself including your age, race, income, educational level, and how long you have been caregiving.

You and your care-recipient may also be observed once. The investigator, Allison Lindauer, will watch you and your care-recipient do a task (for example, preparing a meal). You may choose the task. The investigator will not interview you during the observation, but may ask you questions about what you are doing. This observation will take about one hour.

During this study you will be audiotaped*.*

Each interview session will be audio-recorded. The recording session will last as long as the interview (1-2 hours). The recordings will be transcribed and the written transcripts used for the study. The audio-recordings will be destroyed when the study is finished.

If you have any questions regarding this study now or in the future, contact **Theresa Harvath** (503) 494-3855 or **Allison Lindauer** at (503) 449-8151.

RISKS AND DISCOMFORTS:

During the interviews, some of these questions may seem very personal or embarrassing. They may upset you. You may refuse to answer any of the questions that you do not wish to answer. If the questions make you very upset, we will give you information so you can arrange for assistance.

BENEFITS:

You may or may not personally benefit from being in this study. However, by serving as a subject, you may help us learn how to benefit African American caregivers in the future.

ALTERNATIVES:

You may choose not to be in this study.

CONFIDENTIALITY:

We will take steps to keep your personal information confidential, but we cannot guarantee total privacy.

Under Oregon Law, suspected child or elder abuse must be reported to appropriate authorities.

COSTS:

It will not cost you anything to participate in this study. We may request your social security number in order to process any payments for participation.

You will receive $20 for each interview to help with the costs of care for your family member during the investigator’s (Allison Lindauer’s) visits.

LIABILITY:

If you believe you have been injured or harmed while participating in this research and require immediate treatment, contact **Allison Lindauer: 503-449-8151*.***

You have not waived your legal rights by signing this form. If you are harmed by the study procedures, you will be treated. Oregon Health & Science University does not offer to pay for the cost of the treatment. Any claim you make against Oregon Health & Science University may be limited by the Oregon Tort Claims Act (ORS 30.260 through 30.300). If you have questions on this subject, please call the OHSU Research Integrity Office at (503) 494-7887.

PARTICIPATION:
If you have any questions regarding your rights as a research subject, you may contact the OHSU Research Integrity Office at (503) 494-7887.

You do not have to join this or any research study. The observation part of the study is optional. You can choose not to participate in the optional part but still participate in the rest of the study.

If you do join the study and later change your mind, you have the right to quit at any time. If you choose not to join any or all parts of this study, or if you withdraw early from any or all parts of the study, there will be no penalty or loss of benefits to which you are otherwise entitled, including being able to receive health care services or insurance coverage for services. Talk to the investigator if you want to withdraw from the study or change which parts of the study you are participating in.

The information that we will collect from you will not be stored with your name or any other identifier. Therefore, there will not be a way for us to identify and destroy your materials if you decide in the future that you do not wish to participate in this research.

We will give you any new information during the course of this research study that might change the way you feel about being in the study.

PARTICIPANT OPTIONS

The optional portion, the observation session, is discussed in this consent form and listed here as a summary. Please read the option and place your initials next to it. You can still participate in the main part of the study even if you choose not to participate in the optional part.

_____ I give my consent to participate in the optional observation session.

SIGNATURES:

Your signature below indicates that you have read this entire form and that you agree to be in this study.

We will give you a copy of this signed form.

Subject Printed Name	Subject Signature	Date
Person Obtaining Consent Printed Name	Person Obtaining Consent Signature	Date

OREGON HEALTH & SCIENCE UNIVERSITY
INSTITUTIONAL REVIEW BOARD
PHONE NUMBER (503) 494-7887
CONSENT/AUTHORIZATION FORM
APPROVAL DATE

Oct. 16, 2013

Do not sign this form after
the expiration date of: **10-15-2014**

OREGON
HEALTH & SCIENCE
UNIVERSITY

IRB#: 9777

Research Consent Summary

You are being asked to join a research study. You do not have to join the study. Even if you decide to join now, you can change your mind later.

1. The purpose of this study is to learn more about how African American caregivers understand the changes they see in family members due to dementia (memory loss).
2. We want to learn
    a. About the meaning African American caregivers give to the dementia-related changes they see in their family members and
    b. What are the emotional responses to these changes
3. If you join the study, you and your caregiver will be observed once doing a task together (such as preparing a meal). This will happen only once for 1 hour.
4. There is a small risk of breach of confidentiality.
5. If you agree, information collected during the study may be saved for future research.

OREGON HEALTH & SCIENCE UNIVERSITY

IRB#: 9777

Research Consent and Authorization Form

TITLE: The Meaning of Dementia-related Changes in Persons with ADRD: An Interpretive Phenomenological Exploration of African American Caregivers' Perceptions

PRINCIPAL INVESTIGATOR:	Theresa Harvath, PhD, RN, CNS (503) 494-3855
CO-INVESTIGATOR:	Allison Lindauer, RN, FNP, Doctoral Student (503) 449-8151

PURPOSE:

You have been invited to be in this research study because you are a person with dementia (memory loss) and your caregiver is African American. The purpose of this study is to explore the meaning African American caregivers give to the changes in their family members with dementia (memory loss) and the feelings caregivers have about these changes.

You and your caregiver will be observed by the investigator (Allison Lindauer) once for one hour.

10-30 participants will take part in this study.

PROCEDURES:

You and your caregiver will be observed once. The investigator will watch you and your caregiver do a task (for example, preparing a meal) and take notes. You may choose the task. The investigator will not interview you during the observation but may ask you questions about what you are doing. This observation will take about one hour.

You will be asked to provide minimal information about yourself including your age, race, and how long your caregiver has been helping you.

In the future, the notes from the investigators observation may be given to investigators for other research studies. The notes will be labeled as described in the **CONFIDENTIALITY** section.

The observation session will not be audiotaped, but the investigator will take notes.

If you have any questions regarding this study now or in the future, contact **Theresa Harvath** (503) 494-3855 or **Allison Lindauer** at (503) 449-8151.

RISKS AND DISCOMFORTS:

During the observation, you may be uncomfortable having the investigator in your home. You may stop the observation session at any time and ask the investigator to leave.

BENEFITS:

You may or may not personally benefit from being in this study. However, by serving as a subject, you may help us learn how to benefit African American caregivers in the future

There is no reimbursement for the observation session.

ALTERNATIVES:

You may choose not to be in this study.

CONFIDENTIALITY:

We will take steps to keep your personal information confidential, but we cannot guarantee total privacy.

Under Oregon Law, suspected child or elder abuse must be reported to appropriate authorities.

Data (observation notes) from this study may be shared with other investigators for future research studies All identifying information about you will be removed from the transcripts before they are released to any other investigators.

COSTS:

It will not cost you anything to participate in this study.

LIABILITY:

If you believe you have been injured or harmed while participating in this research and require immediate treatment, contact **Allison Lindauer: 503-449-8151.**

You have not waived your legal rights by signing this form. If you are harmed by the study procedures, you will be treated. Oregon Health & Science University does not offer to pay for the cost of the treatment. Any claim you make against Oregon Health & Science University may be limited by the Oregon Tort Claims Act (ORS 30.260 through 30.300). If you have questions on this subject, please call the OHSU Research Integrity Office at (503) 494-7887.

PARTICIPATION:

If you have any questions regarding your rights as a research subject, you may contact the OHSU Research Integrity Office at (503) 494-7887.

You do not have to join this or any research study. The observation part of the study is optional. You can choose not to participate in the optional part but your caregiver can still participate in the rest of the study.

If you do join the study and later change your mind, you have the right to quit at any time. If you choose not to join any or all parts of this study, or if you withdraw early from any or all parts of the study, there will be no penalty or loss of benefits to which you are otherwise entitled, including being able to receive health care services or insurance coverage for services. Talk to the investigator if you want to withdraw from the study.

The information that we will collect from you will not be stored with your name or any other identifier. Therefore, there will not be a way for us to identify and destroy your materials if you decide in the future that you do not wish to participate in this research.

We will give you any new information during the course of this research study that might change the way you feel about being in the study.

SIGNATURES:

Your signature below indicates that you have read this entire form and that you agree to be in this study.

We will give you a copy of this signed form.

______________________________	__________________________	_____
Subject Printed Name	Subject Signature	Date

OR

______________________________	__________________________	____
Authorized Representative for Research	Authorized Representative for Research (ARR) Signature	Date

(ARR) Name

____

ARR Address

____

ARR Phone

____

ARR Relationship to Care-Recipient

____

Date of Designation

__________________________	_______________________	_____
Person Obtaining Consent Printed Name	Person Obtaining Consent Signature	Date

OREGON HEALTH & SCIENCE UNIVERSITY
INSTITUTIONAL REVIEW BOARD
PHONE NUMBER (503) 494-7887
CONSENT/AUTHORIZATION FORM APPROVAL DATE

Oct. 16, 2013

Do not sign this form after
the expiration date of: **10-15-2014**

Appendix F

Demographic Information

Age:

Race:

Age of Care-recipient:

Race of Care-recipient:

Education (highest level of schooling completed):

Relation to care-recipient:

Number of months caregiving:

Number of hours/month caregiving:

Income adequacy:

Which of the following four statements describes your ability to get along on your income?

I can’t make ends meet	1
I have just enough, no more	2
I have enough, with a little extra sometimes	3
I always have money left over	4

Income:

What is the total amount of your yearly household income before taxes? Include the income of your family member if he or she lives with you. Please select one of the following categories:

1. Under $5,000
2. $5,000 to $7,499
3. $7,500 to $9,999
4. $10,000 to $12,499
5. $12,500 to $14,999
6. $15,000 to $19,999
7. $20,000 to $24,999
8. $25,000 to $29,999
9. $30,000 to $34,999
10. $35,000 to $39,999
11. $40,000 to $49,999
12. $50,000 to $59,999
13. $60,000 to $74,999
14. $75,000 to $99,999
15. $100,000 to $149,999
16. $150,000 and over

Appendix G

Interview Guide

Interview Guidelines	
Consent	- Ask participant if she has any questions about the study. - Advise investigator is mandatory reporter of Elder or Child Abuse - Review consent form.
Start of interview	- Start by reminding participant that the interview will be audio-recorded and her participation is entirely voluntary. She may stop the interview at any time.
First Questions	The first set of questions is to help the participant become comfortable and to get a sense of the family's background.
Advance to next questions	- Ask about day-to-day activities. - Listen for themes of the meaning of change.
Emotion-focused questions	Move on to the more emotional issues.
Caregiver distress	If caregiver appears to be having difficulty managing emotions, offer to change to a different question or end the interview. If participant seems to need emotional support, offer handout with 211 and Alzheimer's Association phone number.
Notes	Take notes using "Interview/Observation Note Pages" (below)
Conclusions	- End by focusing on strengths. - Not all questions need to be used.
Key points	Work on keeping investigator comments to a minimum.
Wrap-up	Check for the following: ○ Participant has copy of informed consent ○ Give thank you letter with $20.00 cash ○ Stop recording, pack up recorders ○ Pack up notepapers, pens, pencils ○ Thank participant

Interview Questions

1. Set up
    - b. Make sure participant is comfortable.
    - c. Set up audio recorders, turn both on, position microphones.
    - d. Set tissue near participant in case of need.

2. Introductory Ice Breakers
    - a. I'm interested in knowing a little bit about your mother. Can you tell me where she grew up?
    - b. Can you tell me a story about what she was like when you were younger?

3. Caring in the Present
    - a. Please tell me about a typical day caring for your mom.
    - b. What's life been like since you started caring for your parent?
    - c. Please tell me a story about when you first noticed the changes in your parent (or when your parent was diagnosed with dementia).
    - d. What was it that made you wonder if your parent had dementia?

4. Emotional issues
    - a. Do you find there are things you miss about your mother?
    - b. Some people tell me they feel their parent is *gone* even though they are still alive. Have you had this experience?
    - c. Can you tell me what it means to you to see your mother change?
    - d. What do you think the future holds?

5. Wrapping up
    - a. How do you take care of yourself?
    - b. What gives you strength?
    - c. Are you a religious person? If yes, have your religious practices helped you? Explain.
    - d. What advice would you give other caregivers?

Appendix H

Observation Guide for Study

Observation Guidelines	
Prior to observation	○ Arrange time, date and activity with participant. ○ Have participant and care-recipient read information sheet and provide verbal consent from care-recipient. ○ Remind family the investigator is mandatory reporter of elder and child abuse
Observation	○ Ask caregiver to designate place for investigator to stand or sit so she is not in the way. ○ Remind family that you will be taking notes but not audio-recording. ○ Tell family to go about regular tasks ○ Keep investigator comments to a minimum. ○ Remind family this is only to watch interactions, not to judge or critique caregiver skills. ○ Note time ○ Write notes using "Interview/Observation Note Pages" (below)
Conclusion	○ End at completion of task or after 1 hour of observation. ○ Ask family if they have any questions ○ If caregiver appears unduly stressed, offer resource page
Wrap-up	Check for the following: ○ Participant has copy of informed consent ○ Give thank you letter with $20.00 cash ○ Pack up notepapers, pens, pencils ○ Find keys ○ Thank family

Interview/Observation Note Pages

Demographic Information	**Descriptive Notes**	**Reflexive Notes**
Date, pseudonym, setting	Account of Activity	Ideas, feelings, hunches

Appendix I

Resources for Caregivers

Caregiving can be overwhelming at times. If you need to talk to someone, you can call these numbers:

Multnomah County Aging and Disability Services:
- Information and referral
- 503-988-3646

Multnomah Crisis Line
- Support and referral for urgent issues (anxiety, depression, family violence)
- 503-988-4888

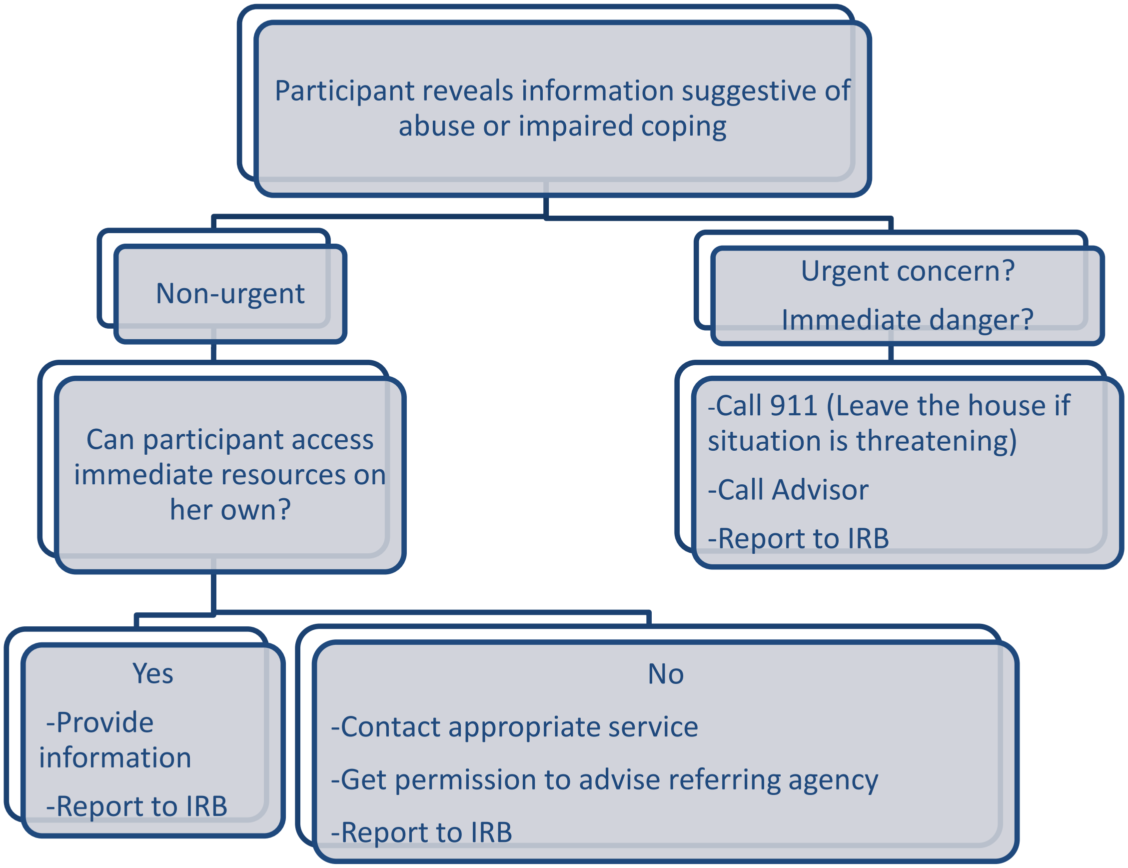
Multnomah and Clackamas Counties:
- Information and referral
- Dial 211

Alzheimer's Association 24/7 Helpline
- For any family coping with memory problems of any type. This service provides many types of help, from information to emotional support.
- 1-800-272-3900

Appendix J

Decision Tree

Decision Path for Concerning Situations



Appendix K

Permission Letter

Dear Allison:

Thank you for your request.

Permission is granted for you to use the material requested for your thesis/dissertation subject to the usual acknowledgements and on the understanding that you will reapply for permission if you wish to distribute or publish your thesis/dissertation commercially.

Permission is granted solely for use in conjunction with the thesis, and the material may not be posted online separately.

Any third party material is expressly excluded from this permission. If any material appears within the article with credit to another source, authorisation from that source must be obtained.

Sincerely,

Paulette Goldweber
Associate Manager/Permissions-Global Rights
Professional Development

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