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Caregiver Support within the Dementia Context: Best Practices in Responding to Ambiguous Loss

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by

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MSW Clinical Research Paper

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The Clinical Research Project is a graduation requirement for MSW
students at St. Catherine University/University of St. Thomas School
of Social Work in St. Paul, Minnesota and is conducted within a
nine-month time frame to demonstrate facility with basic social
research methods. Students must independently conceptualize a
research problem, formulate a research design that is approved by a
research committee and the university Institutional Review Board,
implement the project, and publicly present their findings. This
project is neither a Master's thesis nor a dissertation.

Abstract

The purpose of this study was to use the concept of ambiguous loss as a lens to explore common challenges that family caregivers experience when caring for a loved one with dementia. This study attempted to collect qualitative data from licensed social workers who have experience working with family members and their diagnosed loved ones. Key findings made in this study include the different forms in which ambiguous loss may cause distress on behalf of caregivers: A physical presence yet psychological absence (an example of boundary ambiguity) on behalf of the diagnosed individual, the loss of future potential on behalf of spousal-caregivers, and role changes within the family system. Other findings include the tendency for caregivers to isolate themselves from outside support due to the private nature of caregiving and a possible stigma against support group attendance. Research recommendations as well as recommendations to social workers within the dementia context are also discussed. Given the relative infancy of the current research base regarding ambitious loss within the dementia context, it is important that future studies continue to examine the nuanced form of grief that individuals face when caring for a loved one with a neurodegenerative disease.

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Introduction

Ever since Jean had gotten married and moved out of state, her mother Rose would call

at 5:15 PM every evening. Despite the geographic distance between mother and

daughter, quarter-after five was their time for one another. As the two grew older, Jean

began noticing a change – instead of 5:15 PM, the phone calls began coming at 6:15 PM.

"This is weird," Jean thought, "My mother has always been on time with the call

throughout the years." Eventually, her mother began calling every third day, instead of

daily. This only added to the daughter's concern. Then, the phone calls came at 5:15

AM. Finally, her mother forgot to call altogether. For Jean, it wasn't the specific time of

the call that mattered; it was the daily connection she shared with her mother.

Eventually, Rose was diagnosed with moderate-stage Alzheimer's disease.

The experience of caring for a loved one with dementia is marked by gradual losses such as the

one experienced by Jean and Rose. Those who have experience with dementia are aware of the

emotional strain that it places upon the family system. Neurodegenerative disorders such as

Alzheimer's disease have often been referred to as "the long goodbye," during which time the

affected individual slowly loses cognitive capacity (Dupuis 2008). As the first wave of baby-

boomers reach age 65, the United States finds itself at a critical moment in history with regard to

how we respond to dementia. For every five years a person lives after the age of 65, their

chances of being diagnosed with some form of dementia doubles (Alzheimer's Association

2013). Social work professionals can use this awareness of population trends to anticipate the growing number of families caring for a member with dementia. In fact, recent studies indicate an increased prevalence on both domestic and international levels (Brayne, Stephan, & Matthews 2011; Brokkemeyer, Evans, Herbert, Langa, Branda, Plassman, & Kukull 2011). This increase comes at a dramatic cost. Looking exclusively at US costs - payments for health care, long-term care, and hospice for individuals with Alzheimer's and other dementias are projected to be $183 billion (Alzheimer's Association 2011). Harder to measure, however, is the emotional toll that dementia places upon the individual and family system. There has been extensive research regarding the psychological and behavioral impact of caregiving within the dementia context (Sara & Adams 2005), however it has only been within the last few decades that a school of research has emerged that sets out to examine the burden on families in order to understand why and how caregiving within the dementia context can have such disruptive capabilities.

Throughout the past thirty years, the examination of ambiguous loss and boundary ambiguity has been used to describe and predict the negative effects that uncertainty has upon the individual (Boss, Greenberg, & Pearce-McCall 1990). Ambiguous loss, along with boundary ambiguity, are concepts that have been championed by Pauline Boss (2004) and illustrate the extent to which uncertainty and change can cause psychosocial distress within the individual. Recent studies have used boundary ambiguity as a lens to physically measure possible challenges inherent with blended families, divorce, and military families (Boss 1977; Cole & Cole 1999; Flynn 1995). There has been very little research, however, dedicated to the high boundary ambiguity circumstance of families caring for a loved one with dementia. Boss, Greenberg & McCall (1990) define high boundary ambiguity as the perception of a family member that is

psychologically present, yet physically absent (as can be the case in families with a missing member), or vice versa. In the case of those caring for individuals with dementia, a family member may be physically present, yet psychologically absent regarding their cognitive ability and lack of insight. This creates a situation where the family boundary is ambiguous. While boundary ambiguity may be a relatively new concept in terms of research, the feeling of uncertainty that is inherent in loss and change is nothing new in terms of the human experience. Sara & Adams (2005) examined possible psychological effects of such loss and change amongst caregivers of individuals with Alzheimer's disease. Their research illustrates a positive correlation between feelings of grief amongst caregivers and the presentation of depressive symptoms. One study gathered data from 122 family caregivers to individuals with dementia, and implemented the Marwit and Meuser Caregiver Grief Inventory (MM-CGI) and the Geriatric Depression Scale (Brink et al. 1982). When compared to the MM-CGI, the average scores of study participants indicated that approximately 10 percent would be categorized as at risk of serious grief reactions.

This particular study expands Sara & Adams' (2005) examination of caregiver burden within the dementia context by adding the lens of ambiguous loss. Through a qualitative analysis of interviews with social workers who facilitate caregiver support groups, the research hopes to draw upon clinical wisdom to identify best practices that support the biopsychosocial wellbeing of family caregivers. By identifying themes within clinical interventions that acknowledge the nuanced ways in which caring for someone who is physically present yet psychologically absent (characterized by high boundary ambiguity) can affect psychosocial functioning, social workers can become better informed on how to address the burdens amongst caregivers. The following exploratory study will set out to answer the following research questions: What are common

challenges that family caregivers experience when caring for a loved one with dementia? How does ambiguous loss complicate the grief process for caregivers within the dementia context? As social workers, how can we use this information to provide informed support?

Literature Review

      A close analysis of the literature concludes that despite current research surrounding

ambiguous loss as it relates to caregiver support, studies that examine the interaction of these two

concepts within the dementia context may require more development. Such an examination

requires an understanding of the current state of dementia research, a working definition and core

assumptions of ambiguous loss, and how ambiguous loss theory has been applied thus far in

practice. These areas are explored in depth below.

Defining Dementia

      While Alzheimer's disease is often the focal point of dementia studies - it accounts for

one-half to three-fourths of all dementia cases (Gale 2006) - this study will refer to dementia as a

general diagnosis which includes Alzheimer's disease, frontotemporal dementia, vascular

dementia, and dementia as a result of Lewy Body disease. Regardless of the specific diagnosis,

the caregiver experience of distress is often the same and will therefore be looked at collectively

in this study. Dementia will be defined as a degeneration of the cerebral cortex and the

presentation of neurofibrillany tangles and senile plaques within the brain (Gale 2006).

      Regardless of the specific type of dementia, professionals often define the

neurodegenerative process in terms of stages. Designated categories such as "early," "middle,"

and "late" dementia help both medical professionals and family understand and possibly make

sense of the disease. Recent research has even worked towards creating frameworks to assist

with the staging of preclinical Alzheimer's disease (Sperling, Aisen, Beckett, Bennett, Craft,

Fagan, Iwatsubo, Jack, Kaye, Montine, Park, Reiman, Rowe, Siemers, Stern, Yaffe, Carrillo, Thies, Morrison-Bogorad, Wagster, Phelps 2011).

Prevalence

Currently, no medications have been shown to prevent or cure dementia. Medications are used, however, to treat the behavioral and cognitive symptoms and have no effect on the underlying pathophysiology (Rafii & Aisen 2009). While strategies for prevention may not be known, it is clear that the prevalence of dementia is steadily increasing worldwide. Estimates show that numbers of those affected will double every 20 years to more than 80 million by 2040, two thirds of which will live in low and middle income countries (Ferri 2009). This yearly increase is mirrored in the United States, where by 2025 it is estimated that the number people aged 65 and older with Alzheimer's disease will reach 7.1 million; this is a 40 percent increase over current figures (Alzheimer's Association 2013).

Financial and Emotional Costs

In addition to measuring dementia in terms of prevalence, the impact of the diagnosis can also be measured in terms of financial and emotional costs. For many individuals and families, dementia can represent a significant financial burden. The yearly cost per person ranges between $41,689 to $56,290 and Medicare paid approximately $11 billion of the $215 billion total monetary cost in 2010 (Hurd, Martorell, Delavande, Mullen, & Langa 2013). These figures stand to increase given future projections.

The Alzheimer's Association of America has published numerous studies examining the

societal and emotional toll that such neurodegenerative diseases have upon the individual and

family. In 2010, nearly 15 million families and other caregivers provided an estimated 17 billion

hours of care to people with Alzheimer's disease and other dementias (Alzheimer's Association,

Thies & Bleiler 2011). One study set out to examine the burden experienced by families

providing care to a loved one with dementia, paying specific attention to possible psychosocial

changes (Papastavrou, Kalokerinou, Papacostas, Tsangari & Sourtzi 2007). Data was gathered

from a volunteer sample of 172 caregivers between 2004 and 2005 using the Memory and

Behavior Problem Checklist, Burden Interview, Center for Epidemiological Studies –

Depression scale, and Ways of Coping Questionnaire; the results showed that 68% of caregivers

were highly burdened and 65% showed depressive symptoms (Papastavrou et al. 2011). In

conjunction with Sara & Adams' (2005) study, these show that caring for individuals with

dementia affect both individual and group (family) levels of functioning.

Pharmacological Responses to Dementia

While dementias such as Alzheimer's still has no cure, physicians often prescribe

medications that can help manage the symptoms of the disease. One such medication,

cholinesterase inhibitors, boosts the amount of the chemical messenger acetylcholine that is

important for memory, thought and judgment. This type of medication tries to counteract the

dementia-related process that decreases levels of acetylcholine in order to prolong the experience

of memory loss (Mayo Clinic 2014). Additional studies have been conducted regarding the

protective role of certain vitamins against dementia; however, current research does not show

results in the reduction of Alzheimer's disease (Savica & Petersen 2011). Another form of

pharmaceutical, N-methyl-D-aspartate (NMDA) has been approved for the treatment of

moderate to severe Alzheimer's disease (Reisberg, Dondy & Stoffler 2003). However as Savica

& Peterson (2011) comment, when considering the role of pharmaceutical therapy with dementia

it is important to remember, "Although somewhat useful in treating individuals with Alzheimer's

disease, [pharmacological responses] do not appear to have any effect on prevention of the

symptomatic phase of Alzheimer's disease" (p. 131).

Preventative Measures

Research has found that physical and intellectual activities may help reduce the risk of

developing dementia in later-life (Lautenschlager, Almeida, & Flicker 2004; Verghese, LeValley

& Derby 2006). One study sought to compare the cognitive abilities of individuals over the age

of 50 who were given 24 weeks of physical exercise or an educational program. The subjects in

the exercise group reported better cognitive scores than those in the educational program

(Lautenschlager, Cox & Flicker 2008). Furthermore, exercise has been shown to decrease

morbidity and mortality while increasing quality of life, this may serve to protect an individual

from developing cognitive disorders, however further research is needed (Savica & Peterson

2011).

Research also suggests a positive correlation between intellectual activity and reduced

risk of Alzheimer's disease (Verghese, Lipton & Katz 2003). The Seattle Longitudinal Study

followed over 5,000 subjects for four decades to examine the role of intellectual actives and risk

of cognitive decline (Schaie 1996) - The study found that an intellectually stimulating environment may reduce the risk for cognitive decline in later life.

Defining Ambiguous Loss

While there are many definitions of ambiguous loss, most center on uncertainty and interrupted grief. As Betz & Thorngren (2006) explain, "The premise of the ambiguous loss theory is that uncertainty or a lack of information about the whereabouts or status of a loved one as absent or present, as dead or alive, is traumatizing for most individuals, couples and families" (p. 359); furthermore, this uncertainty freezes the grief process, causing sustained distress on behalf of the caregiver (Boss 1999). It is in this way that ambiguous loss functions as a way (or lens) to view biopsychosocial effects of grief and loss on the individual. When applied to the dementia context, another concept related to ambiguous loss must be considered – boundary ambiguity. Boss, Greenberg, & McCall (1990) define boundary ambiguity as a perception of a family member as being physically present yet psychologically absent as is the case with dementia where a physical presence may be accompanied by a progressive decrease in cognitive ability and insight.

Core Assumptions of Ambiguous Loss Theory

An understanding of how the concept of ambiguous loss has been developed as a practice theory can be conveyed through an analysis of Pauline Boss's (2007) article "Ambiguous Loss

Theory: Challenges for Scholars and Practitioners." Such an examination sheds light on some of the core assumptions of the theory.

First, ambiguous loss theory assumes that a psychological family exists and may differ from traditional definitions (Boss 2007). When working with both individuals and families regarding ambiguous loss, it is important to have the client define who is "in" or "out" of their particular family system. It is in this respect that one's psychological family becomes more relevant than physical family. This is especially true when working with cultures that have definitions of families with more elastic boundaries (McAdoo 1995), as well as in families of choice, when individuals create family-like relationships among non-related people.

Second, it is assumed that a phenomenon can exist even if it cannot fully be measured (Boss 2007). This is paramount in relation to ambiguous loss, as it is virtually impossible to engage in a conversation about it that doesn't deal with at least a small amount of abstract reasoning. As Boss (2007) explains, "[Reliability] does not make sense in assessing a perceptual phenomenon (such as ambiguous loss) that is expected to change over time" (p. 106). It is for this reason that qualitative studies are preferred, as it allows the researcher to ascertain data from abstract concepts and themes. To accommodate this, boundary ambiguity functions as an observable measure of ambiguous loss. The importance of psychological family, and inherent abstractness of the theory provide the conceptual groundwork for ambiguous loss as it will be defined and considered in this study.

Application of Ambiguous Loss in Practice

Within recent decades, ambiguous loss research has been applied to inform practice (Boss 1999; Betz & Throngren 2006) and has provided recommendations for clinical work including treatment. Boss (1999) provides a qualitative analysis that uses case examples for understanding the multitude of possible situations that produce ambiguous loss, and describes treatment recommendations for practitioners. She observes that along with an increase in managed care come restrictions that require an increase in family home care for their loved ones. Furthermore, this increased contact between caregiver and care-receiver increases the prevalence of ambiguous loss - "[The caregivers'] frequently noted depression probably has more to do with the ambiguity of their loss than their heavy workload" (Boss 1999, p. 4). This knowledge, paired with the statistics of increased dementia, indicates that ambiguous loss will become a greater issue to be aware of in the coming years. As far as practice recommendations, Boss (1999) stresses the importance of creating a care plan that focuses on the family's unique method of coping with ambiguity and making sense of it, rather than concentrating on explaining the specific distressing event or illness. Said differently, Boss advocates an approach that weighs environment more heavily than pathology.

Betz & Throngren (2006) build upon Boss's emphasis on making sense of ambiguity by examining a practice model that combines family stress theory with narrative therapy with the intent for families to define losses, assess resources, and develop meaningful narratives about the loss. Their study illustrates that mourning (the grieving process) does not have to unfold in neat stages; family members may need to revisit their ambiguous loss many times throughout the

years (Betz & Throngren 2006). Furthermore, storytelling can transform grief into a growth process rather than simply an emotional barrier to families (ibid. 2006).

Ambiguous Loss within the Dementia Context

With regard to understanding ambiguous loss within the dementia context, Boss, Greenberg, & Pearce-McCall (1990) identify Alzheimer's disease as a prototypic example of a crisis that may produce feelings of ambiguous loss amongst caregivers. Despite the infancy of this particular field of research, the literature thus far has concerned itself with documenting the caregiver experience as it relates to dementia and examining the degree to which boundary ambiguity affects caregiver wellbeing (Carrol, Olson, & Buckmiller 2007).

Dupuis (2008) examined what it was like for family members to experience ambiguous loss. Through a two-step, qualitative research design, the author looked at 61 adult children (38 daughters and 23 sons) who were caring for a family member diagnosed with dementia and who had been placed in a long-term care facility. Using the grounded theory approach to analyze data, the authors reported that ambiguous loss involves a long, on-going process of phases - anticipatory loss, progressive loss, and acknowledged loss - wherein the underlying sense of ambiguity evolves with the progression of the dementia (ibid. 2008). Anticipatory loss applies to a broad range of experiences. One manifestation occurs when a family first becomes aware of a loved one's memory problems in the early stages of dementia. In this stage, the ambiguity is

centered on what the future holds for both the loved one with dementia and the family. As the neurodegenerative process continues, the family moves into a sense of progressive loss. Ambiguity in this phase takes shape with regard to the existence of the loved one with dementia -

as the family may experience them being more "present" one day than the other. The final phase,

acknowledged loss, marks the point in time where short term and long term memory of the loved

one is completely diminished, and the family acknowledges that the individual with dementia no

longer exists as they once remembered him or her to be.

Role of Social Work

The main roles of social workers are that of educator, coach, resource manager and

support facilitator. Social work tasks in this respect include assessment, family planning, crisis

intervention and management, emotional support counseling, and family advocacy. Geriatric

social work with older adults diagnosed with memory loss can happen in a number of settings

including home health-care agencies, geriatric care management, independent and assisted-living

settings, adult health care, nursing homes, and hospitals (McInnis-Dittrich 2014).

Summary

This review of literature illustrated that ambiguous loss is a lens through which to

observe effects of grief, loss, and uncertainty. Clearly, each experience of ambiguous loss is

unique, and should be examined carefully on a case-by-case basis. However, certain common

patterns and experiences can be discerned. This study aims to build upon previous research

related to grief and ambiguous loss and apply it to the experience of family caregiving within the

dementia context in order to identify various ways in which social workers can support family

caregivers in these circumstances.

Conceptual Framework

This study incorporates the conceptual framework of family stress theory (Patterson & Garwick 1994) and the ambiguous loss model (Boss 2006) in order to generate questions for the qualitative interviews. Family stress theory was chosen as the conceptual framework for the current study due to the previous scholarship that attributes it as the conceptual base for the ambiguous loss model (Boss 1987, 2002; Boss & Mulligan 2003). Family stress theory deals with the ways in which stressful life events negatively impact family functioning, and the processes by which families adapt. These stressful events - including those that create chronic stress such as caring for a family member with dementia - often lead to a reorganization within the family system including a restructuring of roles, routines, and expectations. Furthermore, whether or not these stressful events lead to individual maladaptive behaviors may depend largely on the shared meaning that the family constructs concerning, 1) the specific stressful situation, 2) their identity within the family system, and 3) their view of the world (Patterson & Garwick 1994). This shared meaning largely characterizes how families adapt. For the current study, Patterson & Garwick's levels will be repurposed to fit within the dementia care context by

examining the meaning that families construct concerning the specific event of dementia, their changing roles/identities within the family system, and their outward view of the world. This concept of stress and family stress with dementia will inform the research questions asked to the practice professionals.

Benefit of Using Family Stress Theory

According to family stress theory, individual or family dysfunction results from environmental stress. This perspective lifts any sense of guilt away from the individual. As Boss

(2006) explains, "The focus on the stress of ambiguity allows us to go beyond symptom treatment to build on people's individual strengths. Viewing environmental stressors, not a weak psyche or a dysfunctional family, as the source of symptoms gives hope to clients for some positive outcome" (p. 11).

Applying Family Stress Theory

As previously discussed, Patterson & Garwick (1994) focus on how families construct and share meaning on three levels of understanding (the specific stressful situation, roles within the family, and world view). This perspective assumes a blended approach that takes from the *micro*, *mezzo*, and *macro* levels of the ecological systems theory (Bronfenbrenner 1979) - each of which correspond to Patterson & Garwick's levels of family understanding described above.

Family stress theory applied in this particular study will guide the research questions asked of the respondents. Keeping with Patterson & Garwick's previous research on this theory, it will be important for the questions to examine the ways in which professionals understand family members' relationship to the ongoing stress of caregiving within the dementia context on *micro*, *mezzo*, and *macro* systems. Elizabeth D. Hutchinson (2011) provides a description of the micro, mezzo, and macro classification of environmental dimensions. The author provides the following definition: "Microsystems are those that involve direct, face-to-face contact between members; mezzosystems are networks of microsystems of a given person; and macrosystems are the broader influence of culture, subculture, and social structure (p. 13)."

Questions that deal with the micro level will focus on ways that caring for a family member with dementia affects the individual providing care. It is at this level that the caregiver should be examined in his or her own right, independent of outside relationships.

The mezzo level incorporates the family system into the equation by examining how roles, relationships, and identities change due to the presence of the loved one with dementia. It is common for roles and responsibilities to shift throughout the neurodegenerative process. For example, the caregiver typically handles finances and bill paying, as numbers and figures often become confusing for the individual with dementia. Along with new roles and responsibilities come new sources of stress. Questions that are relevant at this level concern themselves with the way in which individuals become distressed by changing roles responsibilities within the family.

The macro level builds in scope from the other two, and addresses how the individual's worldview is changed by their experiences caring for a loved one with dementia. There are numerous studies that correlate caregiving with increased rates of depression (Carrol, Olson, & Buckmiller 2007). It is in this way that one can physically see the effects of ambiguous loss, as individual and world views become challenged. Questions at this level will deal with exploring faulty cognition and behaviors that the caregivers have developed throughout their experience with the dementia including the formation of any stigmas.

As with all contextual frameworks, it is always important to account for one's cultural and religious background. It is a widely held understanding that culture plays a large role in shaping the belief system of our clients. The importance of this concept is reflected in section 1.05 Cultural Competence and Social Diversity of the NASW's Code of Ethics (NASW Delegate Assembly 2008). The same can be said for how culture shapes family meaning. As an example, previous research points to the fact that African-American families typically have more elastic

boundaries (McAdoo 1995) and a more communal focus on home and family (Burton, Winn,

Stevenson, & Clark 2004). Cultural implications have been accounted for in each of the

qualitative interviews, and will be discussed in subsequent sections.

Methodology

Research Design

The purpose of the current research was to gain a better understanding of best practices that relate to caregiver support in the dementia context. In particular, the research explored professional wisdom to uncover common areas of challenges and support needed by caregivers experiencing ambiguous loss. To address the current research question, an exploratory qualitative study was conducted through the use of interviews. Monette, Sullivan & Dejong (2011) state that qualitative research methods seek to understand the personal and subjective experience of individuals. This approach is particularly useful when there is an absence or abstractness of theory (Monette et al. 2011), as is the case in the current research study concerning the operationalization of ambiguous loss (Boss 2007).

Sample

Sample criteria used in this study included the following: Study participants were graduate-level, clinically licensed social workers (LSW or higher) who had at least two years of experience working with family caregivers who were caring for a loved one with dementia. Specific criteria were chosen as a way to select specific social workers with this characteristic.

A snowball sampling technique was used to recruit participants for the research study. The process by which research participants know and identify other members of the same population group characterizes snowball sampling. Snowball sampling was identified as being best suited for studying mutual relationships among population members (Lavrakas 2008).

Protection of Human Subjects

The current research study was submitted for approval to the St. Catherine University Institutional Review Board (SCU IRB) at an Expedited Level of Review before data collection began. The consent form (Appendix B) was explained in detail to every participant as well as questions used in the research instrument. The consent form explained the purpose and background of the study, the confidential and voluntary nature of the study, risks of participating, and means for contacting the researcher. Also, copies of the consent form and a demographic questionnaire were made available to potential participants prior to their decision regarding whether or not to participate. Participants were also given the right to withdraw from the study at any time. Recordings of the interviews were saved on an encrypted USB drive and stored in a locked file at the researcher's house. Audio recordings were destroyed by June 1, 2014. The

transcripts were stripped of any identifying data and stored in a locked file at the researcher's

house. Transcripts were also destroyed by June 1, 2014. Confidentiality was further maintained by identifying interviewees by number. No names were used in the final written product.

Instrument

A research instrument was created for this current study and consisted of two parts. The first part was distributed to identified participants *before* the actual interview along with the consent form in order to gather demographic information about the research participant as well as to assess familiarity with concepts of ambiguous loss and boundary ambiguity. Participants did not require prior knowledge and familiarity of the ambiguous loss concept. If the research participant was unfamiliar with ambiguous loss and family stress theory, the researcher

explained the concepts using foundational literature (Boss 1999; Patterson & Garwick 1994) at the start of the interview. Demographics measured included gender, level of social worker certification, years of experience in the social work field, and agency experience.

The second part of the research instrument dealt with the ways in which the participants address caregiver support. This section collected study-relevant data from the participants in the form of open-ended questions. Topics covered included ways in which the professional responds to the caregiver experience, challenges to efforts to supporting family caregivers, common areas of support needed within the family and amongst the individual, and the effect of changing family roles and responsibilities.

In order to ensure the reliability of the data collection instrument, all questions were subjected to a professional review process with committee members to ensure clarity and scope.

Data Collection

The snowball sampling technique resulted in a nonprobability sample (Lavrakas 2008). Nonprobability samples are often used when it is too difficult to develop a sampling frame of an entire population (Monette et al. 2011). Because of the inherent abstractness of ambiguous loss, the snowball sampling technique made it possible to identify professionals that had a history with applying this concept to their practice within a geographic domain accessible to the researcher.

The snowball sampling process occurred in the following steps: a) Committee members identified 2-3 potential participants for the study; b) Researcher contacted potential participants, informing them how he/she got their name and introduced the study using protocol; c) Researcher distributed questions and consent form so potential participants could review before making a decision to participate or not; d) If interested, potential participants set up an interview

with the researcher; e) If potential participants did not call within one week, the researcher made one follow-up contact to see if they were interested in participating; f) The interview was audio-taped and transcribed, and lasted approximately 60 minutes; g) Each participant was asked for an additional 2-3 names of potential participants and the data collection process was repeated.

The process of data collection included the following: a) Caregiver Support Study Flyer was sent out to possible participants; b) Interested participants contacted the researcher by email; c) Researcher followed up with potential participants and scheduled a time and date to conduct interview; d) Potential participants were provided with consent form and research instrument; e) Researcher audio record interview as well as compiled written notes; f) Data was transcribed from the audio recordings and written notes; g) Transcriptions were wiped clean of any identifying information to ensure confidentiality.

Data Analysis

Data was analyzed through a content analysis of audiotapes in order to identify themes that emerged from the data. Transcripts were analyzed using a grounded theory approach. The grounded theory approach is a method for developing theory in an inductive manner (Berg 2009). The analysis began with a process called open-coding, a technique in which every sentence of the transcript is summarized with a few words to describe the main concept of the statement (Berg 2009). Throughout the open-coding process, theoretical notations were made to guide the exploration of relevant theories and themes (Berg 2009). Codes were then organized into categories. The coding frame that emerged in the initial transcripts informed the axial coding of proceeding transcripts. Themes that were well supported and relevant to the current research question were presented as the findings of the study.

Researcher Bias

A potential area of bias to this particular study is reflected in the researcher's family history and past experiences with Alzheimer's disease. In addition to having cared for someone with dementia, the researcher had an internship at Bethesda Hospital Outpatient Services, and served clients with memory loss and dementia. This may have resulted in prior experiences playing a greater role in the examination of the proposed concepts, as well as a greater sensitivity to identifying possible professional burnout that may affect responses to research questions. This greater interest may have produced more leading questions, however questions were screened by a research committee in order to compensate for any potential bias.

Findings

Sample

Of the 15 social workers that the researcher contacted for a possible interview, four

agreed to participate. Of the four participants, three were female, one was male; three were

licensed as a LSW, one was licensed as a LGSW; participants' years of experience within the

social work field ranged from two to thirty five; participants had an average of 14 years of

experience working with family caregivers within the dementia context. Furthermore, the

participants presented experience within a diverse range of practice settings including assisted

living, nursing home, rehab center, hospital, as well as managed care organization. Only one of

the participants had a prior understanding of concepts related to ambiguous loss and one had

group facilitation experience. As the data will illustrate, participants have supported caregivers

through their experiences of ongoing grief that is characteristic of ambiguous loss. The

qualitative interviews lasted an average of 45 minutes.

After the interviews were conducted, the researcher transcribed the audio recordings and

pulled themes from common words, concepts, and ideas embedded in the data. Two or more

participants sharing similar ideas constituted a theme. Many themes emerged with regard to

common challenges and barriers experienced by caregivers acting as supports to a family

member with dementia. These themes included dementia related education and awareness, role

changes, anger, the tendency to isolate, a stigma against support groups, and cultural

implications regarding care. Given the scope of certain themes, subthemes have been identified

in order to further organize the data. To ensure anonymity, this researcher will refer to the

participants as "Participant 1, Participant 2, etc.

Ambiguous Loss

Questions that prompted responses regarding ambiguous loss included: *How do you help caregivers respond to the physical presence and the psychological absence of their loved one having dementia? How have family members struggled interpersonally?* From the data collected, it was found that three of the four participants identified that family members often feel a sense of ambiguous loss throughout their experience of caregiver, describing caregiver distress based on the fact that their loved one had a physical presence, yet psychological absence as well as the experience of a loss of future potential. While only one of the participants specifically used the term "ambiguous loss" in their responses, many of the caregiver experiences described by the other participants fell in line with the concepts of ambiguous loss, and will be discussed in the following section.

Physical Presence yet Psychological Absence. Per the collected data, the contradiction of being able to see and touch a loved one with dementia (represented by a physical presence), yet unable to connect with them (psychological absence) is a large source of caregiver distress. Participant 4 commented on the caregiver experience:

> "*We have a lot of family members who can't really grasp the idea of their family members losing their memories and forgetting who they are. They see their moms and think that when they come [to visit them at this care facility] they can still have a normal conversation with them about their past*" (Transcript 4, page 1).

To this point, Participant 3 stated that a common description that caregivers have with regard to their loved one with dementia is, "*This is my mom, but it isn't my mom*" (Transcript 3, page 1) To address this, Participant 4 stated, "*I always tell [the caregiver], it's not like you're losing them,*

they're still there... I tell them hearing is the last to go. Continue to talk to them, continue to say

what you're wanting to say" (Transcript 4, page 4).

Loss of Future Potential. Another common experience that contributes to a sense of ambiguous loss is the loss of future potential that comes with receiving a diagnosis of dementia. Being that there are progressive stages of decline associated with the neurodegenerative disease of dementia, oftentimes family members will experience a form of grief that deals with the anticipated loss of functioning within the diagnosed individual. Participant 1 explained a possible impact this could have between a diagnosed husband and his wife, "*I think that [the spouse] is not only losing their loved one throughout this dementia process, but they're losing their own dreams, their own hopes for the future*" (Transcript 1, page 4).

Dementia Education and Awareness

Caregiver Difficulty with Understanding Dementia. Questions that prompted responses regarding caregiver difficulty with understanding dementia included: *What challenges to caregivers present and how do you address them?* Of the four interviews conducted, three participants identified a barrier experienced by caregivers regarding their understanding of dementia as a progressive disease - the changes associated with the disease, courses of treatment, etc. Participant 2 responded, "*That's the biggest challenge, trying to convince people that it's not going to be like it was before [the dementia] because there's a change. It's hard for the family or significant other to understand that*"(Transcript 2, page 2). Participant 4 stated:

"*It's like the family has a difficult time wrapping their minds around the disease and the*

fact that their loved one is changing - they're not like their usual self anymore. A lot of

[caregivers] have a very, very difficult struggle with that" (Transcript 4, page 1).

Participant 3 stated:

"*I think there's a level of acceptance, maybe not acceptance, but recognition - 'My loved*

one is changing, they're getting more forgetful, they're putting on three pairs of pants

and I don't know why.' Maybe they don't accept it or want to recognize the changes"

(Transcript 3, page 1).

Difficulty Preparing for the Responsibilities of Caregiving. Questions that prompted

responses regarding difficulty preparing for responsibilities of caregiving included: *What types of*

support do you find caregivers commonly need? What challenges do caregivers present as

they're caring for loved ones? Two of the four participants identified a difficulty amongst family

caregivers with effectively preparing for the responsibilities associated with caring for an

individual with dementia. The *scope* of caregiving responsibilities was a common word used by

the participants. As Participant 3 explained:

"*Another aspect of the caregiving is not just the supervision, but also doing personal*

care on behalf of the older individual. Now mom or dad is becoming incontinent, they're

losing their ability to sequence so they're not able to perform grooming and hygienic

duties independently, furthermore, they cannot follow verbal directions like they once

could" (Transcript 3, page 2).

Participant 3 also stated:

"*There's certainly a learning curve that goes along with [a doctor's diagnosis] - just of*

what to expect in terms of behaviors, things they might start forgetting, or quirky things

they may start doing or saying. We find them asking, 'How do I manage this? How do I

keep my own sanity while also caring for this person who has become something of a

child" (Transcript 3, page 1).

Further complicating this is difficulty with anticipating exactly what the diagnosed individual's

decline will look like. Participant 4 explains, "*It is very difficult to categorize them as being in*

one stage or another. They can have certain losses in certain areas of functioning. This makes it

difficult for the social worker when trying to communicate needs to the family" (Transcript 4,

page 1).

Role Changes

The collected data showed a widely shared theme of caregiver difficulties related to

changing roles within the family. Questions that prompted responses regarding support groups

included: *How does the changing of family roles affect members? How do you help caregivers*

respond to the physical presence but psychological absence of their loved one? Two of the four

participants provided answers regarding role changes within the family. As will be discussed in

the following paragraphs, distinctions were made between whether the spouse acted as the older

adult's caregiver or the diagnosed individual's adult children, as these two scenarios produce a

unique type form of stress and grief. What was similar, however, was the metaphor of the

demented individual being something like a child. Three out of the four participants used a

metaphor that equated the cognitive decline associated with dementia and the associated

behaviors with that of a child.

Spouse as Caregiver. The data illustrates a difference in experience between spousal and

adult child caregivers. Participant 1 stated:

> "*I think it's harder for the spouse because they are needing to do their tasks and roles,*
>
> *but then they take the roles of their spouse as well. For example, a wife is now suddenly*
>
> *doing the bills, needing to talk to the mechanic about the car, etc. The individual has to*
>
> *make decision on his or her own. I think that's just overwhelming… I think that [the*
>
> *spouse] is not just losing their loved one throughout this dementia process, but they're*
>
> *also losing their own dreams, their own hopes for the future*" (*Transc*ript 1, page 4).

Participant 2's responses largely concurred with this, stating:

> "*It's very hard, especially in a situation where the roles have been reversed. Especially*
>
> *in the older generation, that's how it was [family members having gender-specific roles*
>
> *and responsibilities]. When they were younger, the wife stayed home and did the*

cooking, cleaning, and raising the kids. When those roles are reversed, there are times

when the individual is just not able to function" (Transcript 2, page 4).

    Adult Child Caregivers. The data suggested that adult children who care for a

mother/father diagnosed with dementia experience a changing of roles wherein they act as a

"parent to their parent." Participant 1 explains:

    "*The roles certainly do change. The adult child has to almost become a parent - they're*

    making decisions, they're doing all the things that a parent does for a child. I hate to say

    that the individual with dementia is like a child, but the roles certainly do change"

    (Transcript 1, page 3).

Anger

    Among the emotions participants observed in their work with caregivers, anger was the

most common. Questions that prompted responses regarding anger included: *Have you seen*

caregivers adopt any maladaptive habits? Three out of the four participants identified anger as

being common amongst caregivers within the dementia context. Participant 2 and 3 both

attributed caregiver anger to a general frustration towards the disease. Participant 2 stated:

    "*[Anger is generally directed] towards the person that has the cognitive loss. I think a*

    lot of that comes from not understanding and getting frustrated. [The caregiver] is

    burned out with everything - they haven't been sleeping well. That makes it really hard to

    cope" (Transcript 2, page 3).

Participant 3 described possible results of one caregiver's anger:

"We've had reports from our drivers that things are getting escalated at a certain house.

There may be times when we find some bruising on the older adult, families getting more

physical with the older adult who refuses to go [to day programming]" (Transcript 3,

page 4).

Furthermore, Participant 1 identified a feeling of anger among spousal caregivers experiencing

ambiguous loss as a result of anticipated decline in future potential.

Tendency to Isolate

A tendency for the caregiver to isolate themselves socially during the caregiving process

was another theme pulled from the data. Questions that prompted responses regarding the

tendency to isolate included: *How have family members struggled interpersonally when caring*

for someone with dementia? As Participant 4 explains, "*I feel like [caregivers] think that they are*

alone in this. A lot of them don't know why [dementia] happens, nor do they know the amount of

other caregivers that struggle with the same things" (Transcription 4, page 3). Three out of the

four participants used terms like "isolated," or "alone" to describe how caregivers feel during this

process. All of which, however, identified an uneasiness on behalf of caregivers to seek

assistance in general. As Participant 3 illustrates, it may have something to do with the very

nature of family caregiving:

"I think with some there is an element of privacy to caregiving- 'This is my family

member. My Mom or Dad.' They have always shared an intimate relationship together.

The changes one sees as a caregiver are intimate as well; the response required can be

intimate. Everything about the caregiving process is intimate and private" (Transcript 3,

page 2).

Stigma against the Disease. Another source of isolation may stem from the stigmas

against a disease such as Alzheimer's and other forms of dementia. Two participants identified a

possible stigma against the disease. Participant 1 stated,

"Just as their loved one's circle gets smaller, the caregiver's [social] circle gets

smaller...I think many of their friends don't want to hear about [dementia]. Especially

those over 65 because there's the fear that they might get it themselves. So it's not

uncommon for caregivers to lose a lot of friends that they once had... They don't want to

hear about it and they don't want to be around the diagnosed individual because they're

not the same person they once were - they get uncomfortable" (Transcript 1, page 3).

Stigma Against Support Groups

An Underutilized Source of Support. Among the numerous resources that social

workers recommend to caregivers, support groups may serve as an underutilized, yet deeply

effective source of support. Three out of the four participants provided responses regarding

support groups. Questions that prompted responses regarding support groups included: *What*

types of support do you find that these individuals commonly need? Participant 2 commented that

for many caregivers, attending a support group may seem more of a burden than a benefit:

"I think [caregivers] think of support groups as just another thing they have to add to

their list. 'I already care for my father all day, now you want me to go talk to strangers?'

But I think if they can find the time to get to that one meeting and see how beneficial

support groups can be, they'll make it a priority" (Transcript 2, page 6).

Participant 3 shared this sentiment of caregivers feeling uneasy within the support group milieu:

"I don't think that support groups have been utilized too much and I don't think it's been

as effective for [my caregiver clients]. People are struggling and it's hard to get them to

branch out and talk with some strangers about their experience" (Transcript 3, page 2).

When asked about their opinion regarding whether caregiver were apprehensive towards

attending support groups, Participant 3 stated, *"It wasn't so much apprehension, but it was*

something that they never followed through on. [Support groups] were always something that we

were promoting, but I don't think that there was any follow through for a number of different

reasons" (Transcript 3, page 2).

Participant 4 also recognizes room for improvement, while adding a gender-based perspective:

"I wish there would be more [families that attended groups]. I've noticed that there is a

trend for female family members to attend more than males. We've had male spouses

who have refused to attend a group up until a certain point. It is very difficult in their

process to see their wife in a care unit like this. However, once you can get a

breakthrough in gaining trust and making them aware that they are in the right place,

typically you can get them to attend" (Participant 4, page 2).

Benefit of Groups

   Benefit of Shared Experience. Questions that prompted responses regarding support

groups included: *What types of support do those who care for individuals with dementia*

commonly need? The benefit of shared experience was a present theme in all four of the

participants' responses. Participant 2 commented on the benefit of caregivers learning from the

experiences of their peers:

   "*Part of my role is to talk about what other caregivers have done. We have had some*

   wonderful families who have been caring for their loved one at home. The things they

   put into place at their homes, alarm systems, video cameras, baby monitors) are

   amazing. It's really just giving them ideas of what others have done in their situation

   and connecting with resources" (Transcript 2, page 5).

While the study data identified a possible stigma towards support groups among caregivers who

were thinking about attending, findings also suggest that there is a large benefit of support group

participation that derives from the shared experience that is afforded to group members.

Participant 1 shared their experience facilitating groups in the past, noting:

   "*And the support group was really interesting because what happened over the first year*

   and a half was that the 'older members' [individuals who had attended more groups]

   began supporting newer members. That was the goal on our part as facilitators. Many

times myself and the co-facilitator would just sit back and watch the interaction that took

place between group members" (Transcript 1, page 1).

Participant 3 emphasized the support that comes along with stepping out of one's comfort zone

and attending a caregiver support group, "*If you can get families to go and talk to other families*

that are going through the same thing, they'll realize that they're not alone in the struggle and

can get ideas from each other" (Transcript 3, page 6).

Cultural Implications Towards Receiving Support

Study results also suggest a theme regarding cultural barriers related to the individual

caregiver's age and ethnicity. Questions that prompted responses regarding cultural implications

included: *Do families differ a lot in how they cope with the type of loss dementia presents? Do*

they relate to racial or cultural differences?

Age. Participant 2 observed that spousal-caregivers tend to be less likely to utilize

community-based resources for support:

"*I think people are very stoic - especially in the older generations. They believe that they*

take care of each other. When they made a vow it was going to be for, 'better or for

worse,' and that's what they are going to do no matter the cost. I think they feel as

though they can just do anything and everything - that they can care for the person at

home not realizing how exhausting it's going to be and how much their health is going to

suffer because of it" (Transcript 2, page 1).

Ethnicity. A caregiver's ethnicity may affect their access to certain forms of support.

Participant 2 explains one such manifestation of this concept:

> "*There are different cultures, depending on what it is, that they must definitely believe that they take care of each other. So no matter what, the person is going to go home and [the caregiver] will care for the person at home. Assisted living and long term care is not an option for them at all. It's just how they were raised - everyone takes care of everyone else*" (Transcript 2, page 5).

Connecting this idea to a wider perspective, certain cultures believe in handling issues as a cultural community. Therefore, if a particular resource or support were to be deemed outside of a particular ethnic boundary, individuals would be less likely to participate. Participant 3 commented on differences in trust levels within different cultural communities:

> "*I think an issue that pertains to all of healthcare in general across cultures is the level of trust. Different cultures respond differently to healthcare workers from a different ethnic origin. There's a level of trust that has to happen when one is providing support to caregivers - trust in the directive, 'Your father may still look like your father, however things are happening cognitively that cannot be observed.' There are times when you run into family members that don't trust the information. It may never turn into trust, but it takes a lot of communication*" (Transcript 3, page 4).

Discussion

Sample

The researcher's original interest in conducting this study was to hold qualitative interviews with social work professionals who had experience working with family caregivers. While a relatively small number of interviews took place (n = 4), all of the participants met the study criteria: All four participants were licensed social workers, and each had at least two years of professional experience with families caring for a loved one with dementia. Characteristics that may have influenced responses included gender, personal experience with dementia, and lack of group facilitation experience.

Of the four professionals interviewed, only one was male. While the researcher tried to use a diverse sample, greater gender diversity was not possible given the time constraints of this research. Furthermore, possible bias due to gender was not assessed, yet could have affected answers to research questions.

Another factor that was not assessed in the sample was a personal family history with dementia. While the research study focused mainly on professional experience with caregivers, a first-hand, personal experience *as a* caregiver to an family member with dementia certainly has the potential to affect professional beliefs regarding how to best support dementia caregivers.

As the findings illustrate, support groups and the shared experience that comes with them may play an important role in the lives of caregivers. Of the four participants in this study, only one had prior experience facilitating a caregiver support group, although all had worked with caregivers impacted by dementia. The experience of supporting caregivers in a group format may have provided the participant with a greater range of knowledge regarding the numerous challenges and stresses of caregiving within the dementia context.

How Ambiguous Loss Complicates the Grief Process

      The prevalence of the first theme throughout the qualitative interviews indicated that ambiguous loss is indeed a common source of distress among caregivers within the dementia context. While the participants did not use the concept ambiguous loss by name, there were phrases that could be connected back to idea of ambiguous loss including "inability to connect [with the family member]," "difficulty accepting that something is wrong," and "this is my mom, but it isn't my mom."   The literature previously cited indicates that dementia creates a sense of ambiguous loss among family caregivers stemming from four areas - the unobservable nature of the neurodegenerative process, the sense of anticipatory loss after receiving a diagnosis of dementia, the experience of boundary ambiguity, and changing roles within the family. Again, an interesting point was the fact that while only one of the four participants was familiar with the concept of ambiguous loss, all four were familiar with the sense of prolonged grief and distress that ambiguous loss creates on behalf of the caregiver, suggesting that the concept is a good fit for this particular population.

      One form of ambiguous loss stems from the fact that dementia affects the mind more than the body. Said differently, caregivers may have a difficult time acknowledging or noticing that there is a loss happening due to the fact that, for much of the disease, the diagnosed individual changes cognitively. This type of change is harder for caregivers to observe. This was seen in the data when participants reported that caregivers often struggle with the reality that, "This is my mom, but it isn't my mom." Additionally, the data illustrated that, given the changes associated with dementia are harder to observe, they may serve as a barrier to them fully understanding the disease. The largely unobservable changes associated with a neurodegenerative disease such as dementia may partially explain the designation of stages (early, middle, and late-stage dementia).

Much like how Sperling, Aisen, Beckett, et al. (2011) worked to develop a framework to assist with the staging of preclinical Alzheimer's, using such labels may help to dispel the ambiguous nature of the disease.

The second form of ambiguous loss that the caregiver experiences happen shortly after their loved one receives the diagnosis of dementia. As participant 1 described during the interview, it is common for family caregivers (especially spouses) to reassess future plans after receiving a diagnosis. This often leads to a lost sense of dreams/plans for the future. This feeling of loss corresponds to Dupuis' (2008) study on anticipatory loss. As the author states, "One manifestation occurs when a family first becomes aware of a loved one's memory problems [often times in the form of a doctor's diagnosis] in the early stages of dementia. In this stage, the ambiguity is centered on what the future holds for both the loved one with dementia and the family."

Boss, Greenberg & McCall (1990) define boundary ambiguity as a perception by a family member as being physically present yet psychologically absent. This was a dominant theme from the collected data, as two of the four participants identified boundary ambiguity as a contributing factor of caregiver distress. Similar to the study of Carrol, Olson, & Buckmiller (2007), the collected data of this study emphasizes the importance of understanding boundary ambiguity, as understanding this may help validate client experiences.

Changing roles within the family during the dementia process has also been identified in the data as causing caregiver distress. Whether it was between spousal or adult child caregivers, four of the four participants identified changing roles that caused distress among family caregivers. Interestingly enough, this distress continues after the diagnosed family member is placed out of the home environment within a care facility. Participant 4 reported on this when

describing how families react when their loved one is no longer able to identify them, "I have a lot of family members who shy away from [visiting their family member] just for that reason - they don't feel like their presence is going to help with anything." Participant 4 is identifying the distress when a son is no longer identified as "son" by his parent with dementia. A possible connection to existing literature can be made with Sara & Adams' (2005) study on the presentation of depressive symptoms among family caregivers. While more research has to be conducted before any correlation can be made, it is possible that part of the reason why caregivers develop feelings of depression stems from the changing roles and family dynamics during the decline of the loved one with dementia.

The end result of ambiguous loss is the inability of family members to connect with the diagnosed individual in ways they were once able to connect. Recalling the story at the beginning of this report of the mother and daughter who would call each other at the same time every day, the simple act of connecting with loved ones is an important aspect of maintaining emotional stability. When this ability is lost due to dementia, family caregivers are at a higher risk for experiencing distress. The inability of family members to connect with the diagnosed family member in ways they once did, connects to Boss, Greenberg, & McCall's (1990) work on boundary ambiguity - where individuals are physically present, yet psychologically absent.

Support Groups

Support groups were another theme identified in the study data. It is clear that attending support groups is a lot to ask from our caregivers. As Participant 3 shared, "*I can't say I would be too confident meeting with a group of people and talking about my mom's behaviors or how different aspects of caregiving are going.*" While the participants identified possible barriers to

support group attendance, the benefit of hearing the shared experience inherent in support groups may in fact outweigh the initial apprehension. As previously identified in the study findings, caregiving is typically viewed as a private affair. This sense of privacy often leads caregivers to feel isolated. When attending support groups and hearing other individuals talk about their unique experience of caregiving, the shared experience may alleviate feelings of isolation. Participant 1 commented on this as it relates to a typical outcome of support groups, "*The main thing that comes out of the group is that people say, 'I don't feel alone.' As they experience different problems and issues, the group is there to help them*." Furthermore, hearing shared experiences may normalize emotions and experiences of individual caregivers. As Participant 1 stated, "[In group], people have that connection and they get it because someone else was saying it and acknowledged their feelings." These sentiments are mirrored in the existing literature. Chu, Yang, Liao, Chang, Chen, Lin & Chou (2010) studied the effects that support groups had on dementia caregivers' burden and depression. Their data illustrated that groups were effective for reducing caregivers' depression, but not effective for relieving overall burden of care.

Furthermore, Bank, Soledad, Rubert, Eisdorfer, & Czaja (2006) conducted a similar study regarding support groups for dementia caregivers; their results showed that an the overwhelming majority of participants found support groups valuable due to the social and emotional support as well as the useful information learned from other group members - the shared experience.

An interesting point to make from the collected data is the dichotomous nature of support groups. On one hand, the very nature of groups may be intimidating to caregivers given the personal nature of the disease. Inversely, as the participants indicated, there can be great value in the shared experience that comes with discussing experiences with kindred spirits. It is up to the

social workers, then, to do what they can to promote support groups. A possible way to do this falls in line with Alex Gitterman's mutual aid model (2004) – this model states that by hearing others' experiences helps normalize individual experiences. Along with this come bonds that form between members. As social workers, we can use this idea to create a "buddy-system" where members hold others accountable for group participation. A secondary benefit of this could be a form of mentoring, where established group members dispel any group misconception for newer members.

Role of Social Workers

As a result of the findings of this study, there are numerous conclusions that can be made regarding the role of social workers as it relates to how to best support family caregivers within the dementia context. Mirroring the conclusion that Sara & Adams (2005) had made that caring for individuals with dementia affects both individual and group (family) levels of functioning, the data shows this multi-level effect. Participant 2 commented on the fact that family systems can change during the dementia process, "There are times when we see family systems grow. They become closer with each other, more supportive of each other. And there are times when we see that it is destructive."

Participant 4 commented on the nature of a social worker's relationships with client families, "I've had a lot of family members open up to social workers more than they would to a nurse, just because nurses need to be more clinical and sometimes that is what is steering them away from wanting to open up to them or feeling like their problems are being heard." If this is the case, social workers have a professional obligation to be present to the concerns of family

caregivers. Especially when working on an interdisciplinary team, social workers may be identified by families as the only person caregivers feel comfortable talking to.

When working with caregivers within the dementia context, Boss (1999) emphasizes a plan that focuses on the family's unique method of coping with ambiguity. This was mirrored when Participant A commented on the importance of listening to the caregivers, "[Social workers] have years of professional experience with much more objective experience... At the ground level, it takes a lot of listening. Listening to the words that the caregivers are using - it all has to do with what is meaningful for them. How did they interpret their relationship with the loved one up until now? What type of relationship are they looking to have with their loved one right now?" Participant 3 emphasized the importance of listening when providing care. Adding to the role of social workers, Participant 3 commented on the use of reflective practice, "I think we all want to support caregivers, and there's a lot of different ways to show that. But giving them your time, giving of your face time and conversations on the phone to get them to open up about what's going on, let them talk, listen to their words, maintain reflective practice and putting their words back to them to explore deeper issues."

Limitations / Implications for Future Research

A limitation of this study will be the inability to make generalizations due to the small sample size (n = 4). This small sample size may be partly attributed to the time constraints of this particular research study. Another factor could have been that the initial criteria for a possible sample were too narrow. At first, this researcher wanted to focus specifically on licensed social workers who had experiences facilitating support groups for caregivers to individuals with dementia. After some difficulty finding professionals willing to participate that fit the criteria,

the researcher dropped the emphasis on individuals with group experience. Given the identified

emphasis on support groups from the data, future research on this topic should use a sample of

social workers with group facilitation experience. This could be accomplished by partnering with

the Alzheimer's Association Minnesota/North Dakota chapter, as they sponsor numerous

memory loss support groups. Furthermore, an option to conduct qualitative interviews over the

phone could allow future researchers to access possible participants in different states which

would open up the pool of applicants.

As stated, the small sample size (n < 10) reduces the generalizability of the research

findings. Because of which, the results of the current research must be interpreted cautiously.

Findings may be transferable to other settings but are not generalizable. Further research that

uses a larger sample would produce findings that are more externally valid Despite the small

sample size, the vast majority of findings are consistent with previous research.

Along with this limitation on external validity is the narrow scope of professions that are

represented (only licensed graduate social workers). In order to fully understand the challenges

that caregivers face during the process of dementia, it is necessary to hear from other

professionals including physicians, psychologists, and counselors. Additionally, research that

used a more diverse sample - a wider range of professions other than social workers - would

provide perspectives regarding how other disciplines understand and interpret caregiving roles

and the feelings of loss that dementia engenders. This can be accomplished with a larger study

that allows for more time to be devoted to finding and interviewing research participants.

The use of snowball sampling also presented limitations. The main limitation of snowball

sampling is that it misses people who are isolated from professional networks (Monette et al.

2011). This could be addressed in future research by using a sampling technique that is based on the identification of available programs providing support to families impacted by dementia.

A final limitation is the inherent abstractness of the concept of ambiguous loss. While there continues to be a large research base for ambiguous loss and the effect that boundary ambiguity has on individuals (Boss 1977; Boss 1999; Betz & Thorngren 2006; Boss 2006; Boss 2007; Carroll, Olson, & Buckmiller 2007; Dupuis 2008), further operationalization is needed. One way to expand the study of ambiguous loss would be to assess it using quantitative methods. Monette et al. (2011) comments on the benefit that quantitative studies have on the operationalization of concepts, "Most qualitative researchers hold their conclusions more tentatively, or 'lightly,' especially during early stages of the analysis, because they recognize that additional analysis could lead to reinterpretations or reconceptualizations of the data." Researching through survey sampling of caregivers to those with dementia would provide a more robust sample and include a larger number of closed-ended questions that could later be quantified.

Implications for Practice

The findings of this study offer various implications for social work professionals working with family caregivers. Most importantly, social workers must stay familiar with advances in understanding related to ambiguous loss. The findings from this study can be tied to previous research that emphasizes the impact that ambiguous loss has on the caregiving experience (Boss, Greenberg & Pearce-McCall 1990; Boss 2004; Boss 2006; Papastavrou, Kalokerinou, Papacostas, et al. 2007). Social workers within the dementia context are therefore obligated to understand these concepts in order to provide informed support to family caregivers,

as ambiguous loss is often experienced by family caregivers. This can be accomplished though in-service trainings and continuing education seminars.

Dementia education and awareness was another identified barrier to caregivers within the dementia context. Specifically, family members were unaware of the scope of responsibilities associated with caregiving. Again, social workers must have this awareness and find ways to support the caregiver throughout the different stages associated with dementia. This can be facilitated by third-party agencies such as the Alzheimer's Association who are dedicated to advancing memory loss research and providing education to the general public. Many of these agencies have caregiver resources including 24-hour help-lines that individuals can call for on-the-spot support. Along with this barrier of education and awareness, the data identified that caregivers receive distress from the changing family roles. Social workers can address this within their role as educator and coach to families. Having an open and honest dialogue regarding the changes associated with dementia caregiving can prepare individual family members to anticipate changes before they happen. Social workers should strive to promote family members to be proactive as opposed to reactive to the different stages of decline.

Finally, a large barrier identified by the data was the private nature of dementia caregiving, and the potential for family members to develop a stigma against attending support groups. Interestingly enough, the shared experience found in support groups was identified as a potential support for individuals. As social workers, it is our job to work with families and attempt to diminish this barrier toward support group attendance. Along with education regarding the role of support groups, social workers can promote the use of support groups by families by working to process through any stigmas - to start where the individual is in terms of their reservation towards groups, and promote the benefit of a shared experience.

Conclusion

The purpose of this study was to use the concept of ambiguous loss as a lens to explore common challenges that family caregivers experience when caring for a loved one with dementia. Furthermore, a secondary objective of this research was to use this knowledge to assist social workers working with family caregivers. A strength of this study was its application of ambiguous loss within the dementia context, an area of research that deserves more study. By exploring the nuanced ways in which ambiguous loss changes the grieving process for family caregivers in the under-studied context of dementia, the researcher picked up where Dupuis (2008) left off. Key findings made in this study include: The different forms in which ambiguous loss may cause distress among family caregivers - including a physical presence yet psychological absence (boundary ambiguity), the loss of future potential as observed by spousal-caregivers, role changes within the family system; the tendency for caregivers to isolate themselves from outside support due to the private nature of caregiving and the demands of the role; and a possible stigma against support group attendance. The researcher hopes that future studies regarding caregiver support will be mindful of ambiguous loss. As the data illustrated, while the term *ambiguous loss* is not yet familiar to the general majority, the experience of prolonged grief and "the long goodbye" is an experience that is common to many caregivers.

A research participant left the researcher with the following sentiment at the end of their qualitative interview:

> *"I often find myself telling family members, 'it's not like you have to get them back to the moment of how they used to be.' Why not live in the moment they're in? They might not*

recall who you are, and they're happy enough talking about things they haven't

forgotten. If they are happy with that memory, you can still share a connection with them

in talking about the things they haven't forgotten. You don't necessarily have to get them

to recall a particular memory. You can be with them in the moment"(Participant 4, page

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Appendix A

Research Instrument

Instructions to the respondent: Please review interview questions prior to the interview. In Section A, please fill out appropriate responses based on your experience leading up to the interview. In Section B, feel free to write notes and reactions to questions before this interview, as this will improve the depth of discussion during the interview.

Section A: Demographic Information
Please answer the following questions, and bring to the face-to-face interview.

A. What is your gender? __ Male   __ Female

B. What is your level of licensure?   __ LGSW   __ LICSW   __ LSW

C. How many years of experience do you have in the social work field? _____

D. How many years of experience do you have working with family caregivers? _____

E. Have you led any form of groups for caregivers? If so, what kind and for how long?

_____

F. In what types of settings do you have experience working with family caregivers?

_____

Section B: Open-ended Questions

What challenges/supports do caregivers present and how do you address them? Are they typically on an individual, family, or community level?

What types of support do those who care for individuals with dementia commonly need?

What are some ways that you respond to a caregiver's experience with grief, loss, and uncertainty? Are they on an individual level, family level, or group/community level? Can you provide some examples?

How do you help caregivers respond to the physical presence but psychological absence of their loved one? Upon which level does this support typically occur (individual, family, or group/community)?

Do caregivers typically identify on an individual, family, or group/community level?

Have you seen caregivers adopt maladaptive habits that make their lives more difficult? Can you share some examples?

How have family members struggled interpersonally when caring for someone with dementia?

How does the changing of family roles (common within family systems who are caring for a member with dementia) affect members?

What are ways that you account for the stress that caregivers experience when caring for a family member with dementia?

In your experience of working with the caregiver, has the process of caring for a family member with dementia changed their perception of: the world; illness and diseases; grief, loss, or uncertainty?

What factors help/hinder your efforts to respond to caregivers' experience of grief, loss and uncertainty?

Do families differ a lot in how they cope with the type of loss dementia represents? How do they differ?
> **Have you seen differences that you think relate to racial or cultural experiences and understanding?**

Is there anything else you would like to share that would be useful for this study?

Appendix B

Consent Form

Caregiver Support within the Dementia Context: Best Practices in Responding to Ambiguous Loss

I am conducting a study that will use ambiguous loss as a lens to examine common areas of caregiver distress in order to identify clinical best practices. I invite you to participate in this research. You were selected as a possible participant because you have been identified as someone within the social work profession who facilitates caregiver support groups for family caregivers to loved ones with dementia. Please read this form and ask any questions you may have before agreeing to partake in this study.

This research is being conducted by: Michel Rousseau, a graduate student from the School of Social work, St. Catherine University / University of St. Thomas and supervised by Dr. Michael Chovanec, as well as two professionals from the community.

Background Information:
The purpose of this study is to understand the unique ways in which ambiguous loss affects the wellbeing of caregivers. In particular, the researcher will seek to understand the distress caused by caring for someone who is physically present yet psychologically absent. This research is exploratory in nature and may benefit clinical social workers and client families by adding to the knowledge base of effective caregiver support of the dementia context.

Procedures:
If you agree to be in this study, I will ask you to do the following: Prior to the face-to-face interview complete a brief, seven question demographic questionnaire (which should take approximately 10-15 minutes); Participate in an audio-taped interview that will last approximately 40-60 minutes. The interview will take place at a time and location of your convenience, typically at your work setting or a private secure setting, i.e. library meeting room. In May of 2014, you will receive an invitation to attend the researcher's presentation of the findings. Please note, attendance is optional, and is in no way a requirement for participation in this study.

Risks and Benefits of Being in the Study:
The study has minimal risks. The study has no direct benefits.

Confidentiality:
The records of this study will be kept confidential. Research records will be kept in a locked file

in the researcher's home and all identifying information will be removed from the research

records. At no point in the interpretation or dissemination of this research, will identifying information be available to the public. All audiotapes will be destroyed by June 1st, 2014 and transcripts that have been stripped of any identifying information will be kept for an indefinite period of time.

Voluntary Nature of the Study:
Your participation in this study is entirely voluntary. You may skip any questions you do not

wish to answer and you may stop the interview at any time. If you complete the interview, you

may request that your responses be omitted from the study. Participants are given one (1) week following the face-to-face interview to request that their responses not be used in the data analysis. You will be informed of the date when data analysis begins via email or voicemail (depending on the contact information provided). Your decision whether or not to participate will not affect your current or future relations with St. Catherine University, the University of St. Thomas, or the School of Social Work. Should you decide to withdraw from the data collection process within the designated time frame stated above, data collected about you will not be used in the study.

Contacts and Questions
My name is Michel Rousseau. You may ask any questions you have by contacting me at ████████. **You may also contact my research supervisor, Dr. Michael Chovanec, at** ████████, **as well as Dr. John Schmit, the chair of the St. Catherine University Institutional Review Board at** ████████ **with any questions or concerns.**

You will be given a copy of this form to keep for your records.

Statement of Consent:
I have read the above information. My questions have been answered to my satisfaction. I consent to participate in the study and to be audio taped.

_____   _____
Signature of Study Participant   Date

_____

Print Name of Study Participant

_____   _____

Signature of Researcher   **Date**

Appendix C

Caregiver Support Study Flyer

Michel Rousseau
5933 29th Pl. N.
Crystal, MN 55422
Rous0597@stthomas.edu

Hello,

My name is Michel Rousseau and I am a MSW student under the direction of Professor Michael Chovanec, Ph.D in the School of Social Work, at St. Catherine University and the University of St. Thomas. I am conducting a research study to draw upon clinical wisdom in order to identify best practices that support the wellbeing of family caregivers of loved ones with dementia.

I am inviting the participation of social work professionals who have experience with facilitating support groups for caregivers, who are willing to share their experiences. This study will involve completing a short demographic questionnaire prior to participating in a recorded interview that will take approximately 40-60 minutes. The interview will examine challenges that caregivers in this particular situation face, common areas of support needed by these caregivers, as well as

ways to respond to caregivers' experience of grief, loss, and uncertainty.

Data (audio recordings and the accompanying transcriptions) will be kept in a locked file at my house, where only I will have access to it. Any electronic information will be kept on a password-protected computer. All identifying information within this study will be destroyed by June 2014.

If you are interested in participating, I will provide you with an informed consent form as well as the demographic questions to be completed <u>prior</u> to the interview. Please note that upon agreeing to participate in this study, you will be asked to identify three (3) social workers with the appropriate professional background for possible research participation.

If you have any questions about your rights as a participant in this research, or would be willing to participate, please refer to the contact information listed above.

Thank you for your consideration,

Michel Rousseau