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The Support Group Experience of Older Male Caregivers in Providing Care for a Relative with Dementia

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The Support Group Experience of Older Male Caregivers in Providing Care
for a Relative with Dementia

by

Olivia T. Tise, B.S.

MSW Clinical Research Paper

Presented to the Faculty of the School of Social Work
St. Catherine University and the University of St. Thomas
St. Paul, Minnesota
In Partial Fulfillment of the Requirements for the Degree of
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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.

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Abstract

It is estimated that 40% of caregivers of individuals living with dementia are men (Alzheimer's Association, 2013). As the number of people diagnosed with dementia rises, older male caregivers will increasingly meet the demand for care. Men over the age of 65 may be an especially vulnerable group of caregivers. Support groups are one of the most widely used and popular interventions with family caregivers (Hornillos & Crespo, 2012). However, few studies have examined the support group experience of older male caregivers in providing care for a relative with dementia. This qualitative study explored the caregiving experiences of older male caregivers and their use of a memory loss caregiver support group. Five male caregivers between the ages of 58 and 82 participated in this study. Consistent with past literature, the findings of the present study indicate that overall, older male caregivers find the use of a caregiver support group to be beneficial in providing the practical skills and knowledge needed to provide care for a relative with dementia and also find group to be a safe place for emotional support. The men interviewed for this study share the belief that they face unique challenges as male caregivers and noted that these challenges have led to increased feelings of stress and the need for group support to ease the challenges associated with caregiving.

Keywords: male caregiver, caregiver support group, dementia, group work, memory loss, older adult

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The Support Group Experience of Older Male Caregivers in Caring for a Relative with Dementia

In the United States, the population of adults age 65 and older is increasing at an unprecedented rate. In part, the aging of the baby boom generation (individuals born between 1946 and 1964) is responsible for the rapid growth rate as they began turning 65 in 2011 (AARP, 2011). According to the U.S. Census Bureau (2010), by 2030 the number of adults age 65 and older is expected to double to almost 70 million, accounting for over 20% of the population.

The aging of the population brings about unique challenges. In particular, age is the largest known risk factor for dementia. Dementia is a broad term used to describe a variety of symptoms that affect the brain and cause a progressive decline in cognitive functioning and social impairment (Alzheimer's Association, 2014). Dementia has severe consequences and impacts an individual's memory, judgment, personality, behavior, and speech (World Health Organization, 2012). Eventually, dementia causes impairments significant enough to disrupt an individual's ability to perform everyday activities. Dementia develops most frequently in older adults over the age of 60, though it may develop in individuals as young as 40 (Alzheimer's Association, 2014).

Dementia is not only devastating to the individuals who live with it on a daily basis, but it also significantly impacts the individual's family, friends, and caregivers. It is estimated that 70% of individuals diagnosed with dementia live at home and are primarily taken care of by a family member (Alzheimer's Association, 2013). Providing

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care for a relative with dementia has proven to be a stressful experience characterized by many short-term and long-term sacrifices (Holly & Mast, 2009). Decades of research has indicated that family caregivers live with heightened stress, experience more health issues and experience a higher degree of social isolation than their same age, non-caregiving peers (Van Mierlo, Meiland, Van der Roest & Dröes, 2012).

While the majority of family caregivers are women, it is estimated that 40% of caregivers of individuals with dementia are men (Alzheimer's Association, 2013). The experiences of male caregivers have been mostly overlooked in the literature, and their contributions to caregiving have often been devalued (Sanders, Moreno & Corley, 2008; Kramer, 2002). Older men may be a particularly vulnerable group of caregivers. Past studies have indicated that older male caregivers experienced higher levels of depression, a reduction in emotional support and marital satisfaction, and a decrease in overall life satisfaction compared to their non-caregiving peers (Kramer, 2002).

Support groups play an integral part in helping family caregivers cope with the demands of caring for a relative with dementia. Research has indicated that support groups offer many benefits to caregivers. As a member of a support group, participants have reported improvements in their understanding of dementia, increased confidence in their caregiver roles, and a decrease in social isolation (Golden & Lund, 2009). However, cultural expectations and role conflict may discourage older male caregivers in seeking support for their caregiving role (Kramer, 2002).

The purpose of this research study is to better understand the experiences of older male caregivers in caring for a relative with dementia and their use of group support. By

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using the conceptual framework of small group theory, this study seeks to explore the experiences of older male caregivers in attending memory loss support groups for caregivers. As the number of individuals diagnosed with dementia rises, older male caregivers will increasingly meet their needs for care. It is vital to understand the importance of support groups as an intervention for helping these male caregivers maintain their health and well-being and improve their quality of life (Wiles, 2002).

Literature Review

This review of the literature focuses on family caregiving and the unique challenges older male caregivers face in providing support to a relative with dementia. Male caregivers must adapt to new roles, learn new skills, and be open to new means of support in their lives. These life transitions and the use of a caregiver support group as an intervention will be explored.

Substantial research has been conducted on the care provided to individuals with dementia by family members. A review of the existing literature confirms that caring for a relative with dementia is no easy task. Caregiving is a sacrifice and is often described as a stressful experience associated with adverse outcomes such as depression, anxiety, social isolation, a reduction in physical well-being, and an increase in conflict in work and family relationships (Holley & Mast, 2009; Mitrani, 2006).

Historically, much of the past literature has focused on the experiences of women as the primary caregivers to older family members suggesting that caregiving is a “feminized activity” (Aronson, 1992; Baker, Robertson, & Connelly, 2010; Harris, 1993). Over the past two decades, the importance of men as caregivers has been of increasing

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interest to the research community (Kaye & Applegate, 1990; Kramer, 2000). However, the male caregiver experience and relevant interventions continue to be underrepresented in the literature (Russell, 2004).

Dementia

Dementia is diagnosed, in part, by physicians using criteria found in the *Diagnostic and Statistical Manual of Mental Health Disorders* (DSM). The DSM-5, released in 2013, now includes dementia under the category of neurocognitive disorders (Alzheimer's Association, 2014). Alzheimer's disease is the most common cause of dementia, comprising approximately 60 to 80 % of all dementias reported (Alzheimer's Association, 2014). It is an incurable, progressive, and ultimately fatal disease. It is the 6th leading cause of death in the United States (Alzheimer's Association, 2014). With a gradual onset of symptoms, the disease passes through multiple stages and may last decades (Hodgson & Cutler, 1994). In its early stages, Alzheimer's disease may begin with symptoms such as mild memory loss and confusion, but by its final stages, the individual with Alzheimer's disease ultimately loses the ability to communicate and is dependent on caregivers to provide all personal care (National Institute on Aging, 2012).

As women tend to live longer than men, they account for approximately two-thirds of the Americans with Alzheimer's disease (Alzheimer's Association, 2013). With over 5 million Americans living with the disease, the Alzheimer's Association has named it the "defining disease of the baby boom generation" (Alzheimer's Association, 2013). By 2025, it is estimated that over 7 million adults over the age of 65 will be living with Alzheimer's disease (Alzheimer's Association, 2014).

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Other forms of dementia in older adults include vascular dementia, dementia with Lewy bodies, and Frontotemporal dementia (Alzheimer's Association, 2013). Vascular dementia, thought to account for approximately 10% of reported cases, is the cognitive impairment caused by brain damage resulting from a reduction in blood flow to the brain (Mayo Clinic, 2011). Dementia with Lewy bodies is thought to be the third most common type of dementia in the United States, affecting over 1.3 million individuals. Dementia with Lewy bodies is characterized by progressive cognitive decline, changing levels of confusion and attention, and visual hallucinations. Slowed muscle movements, muscle imbalance, and tremors may also present as symptoms of Dementia with Lewy bodies (Lewy Body Dementia Association, 2012). Frontotemporal dementia accounts for approximately 10-20% of all dementia cases and may be characterized by extreme changes in behavior, language, and personality due to the degeneration of the brain's frontal and temporal lobes (Association for Frontotemporal Degeneration, 2013).

Family Caregiving and Dementia

Family caregivers provide the majority of care to individuals with dementia, attending to their physical, emotional, and financial needs. In 2013, it was estimated that 15.5 million caregivers provided over 17.7 billion hours of unpaid care to their friends and family members with dementia (Alzheimer's Association, 2014). The majority of caregivers tend to be the spouses and middle-aged adult children of the individual living with dementia. Spouses typically provide care for the longest period of time (Holley & Mast, 2009).

Family caregiving is emotionally and physically demanding work. The unique stressors and demands of caring for a relative with dementia are especially high (Kaye &

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Applegate, 1990). Studies have indicated that dementia caregivers are more vulnerable to negative health outcomes than caregivers of other illnesses. Though a small number of studies have explored the positive aspects of caregiving, for example, finding a sense of accomplishment from providing care, many caregivers associated their caregiving responsibilities with a lower level of overall life satisfaction (Chene, 2006; Kaye & Applegate, 1990).

Due to the duration and progressive nature of dementia, there often comes a time when the individual living with dementia may no longer be able to perform self-care or carry out activities of daily living such as eating, bathing, and grooming. In order to keep the individual living at home, caregivers often rely on a variety of formal (social services, home health aides, meal delivery) and informal (family, friends, neighbors) networks of support (Caron, Ducharme, & Griffith, 2006).

Caregiver Burden

Past studies on the caregivers of relatives with dementia discuss caregiver burden at length. Caregiver burden refers to the culmination of stressors that affect a caregiver's physical, psychological, and functional well-being (Kim, Chang, & Rose, 2011).

The level of burden experienced by caregivers may relate to the caregiver's relationship status with the individual with dementia, the presence of behavioral issues in the individual with dementia, and the level of support the caregiver perceives he or she has (Alwin, Öberg, & Krevers, 2010). Caregiver burden not only affects the health of the caregiver, but can also affect the quality of care the individual with dementia receives. More than 80% of Alzheimer's disease caregivers reported high levels of stress and

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almost half reported experiencing depression (Etters, Goodall, & Harrison, 2007).

Furthermore, a study conducted by Schulz and Beach (1999) indicated that caregivers who provided daily support to their spouse and also reported caregiving strain, were 63% more likely to die within four years than their non-caregiving peers. Therefore, finding proper interventions and support to ease the burden of caregiving is vital.

The Male Caregiver

The majority of past research about the male caregivers of individuals living with dementia has focused on the husband as the primary care provider, while research on the role that sons or other male relatives may play in caregiving has been limited (Harris, 2002).

Caregiving requires taking on new tasks and learning new skills (Kramer, 2002). Both husbands and sons reported not feeling prepared for many of the duties of caregiving such as household management and personal care (Harris, 2002).

Husbands. Past studies have differed in their findings of husbands' responses to the caregiver role. Some studies have indicated that that male caregivers are stereotypically stoic and maintain an air of control and composure, while others have asserted that male caregivers may actually experience a wider range of emotions due to caring for their wives during such a vulnerable time (Harris, 2002).

Previous research has found that husbands often view caregiving as a natural extension of their marital responsibilities (Thompson, 2002). They expressed a strong sense of love, pride, commitment, satisfaction, and achievement from their caregiver role, but also felt a sense of sadness and loss (Harris, 2002; Kaye & Applegate, 1990). Harris

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(2002) indicated that many husbands experienced an increase in depression, a decrease in emotional support, and reported a decline in overall marital satisfaction due to their caregiving responsibilities. In one study, over half of the men surveyed expressed that they continued to experience high rates of depression even after placing their spouse in a facility for full-time care (Kramer, 2000).

Sons. Adult sons acting in the primary caregiver role make up approximately 10-12% of caregivers to older adults with dementia. Like husbands, sons reported a sense of commitment and duty to their parents as reasons why they took on caregiving responsibilities (Harris, 2002). While sons did express grief over the changes their parents were experiencing and noted the increased demands on their time due to caregiving, their lives were not as altered by the diagnosis of dementia in the same manner as a husband's life often is (Harris, 2002). Caregiving sons were also able to set better limits on their time spent on caregiving responsibilities. Harris (2002) found that sons might experience less caregiver burden because they may have their own spouse to rely on for support. In addition, sons who provided care were more proactive in finding services to help both their parents and themselves.

Older male caregivers. Men over the age of 65 may be an especially vulnerable group of caregivers. For decades, these husbands have come to rely almost solely on their wives for emotional support and find their lives profoundly disrupted by their wives' dementia (Harris, 2002; Russell, 2004). Older caregivers, especially those sharing a home with their relative with dementia, experience higher levels of burden than younger caregivers (Kim et. al, 2011).

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Gender Differences in Caregiving

Traditionally caregiving has been viewed as “women’s work,” and the nurturing essence of caregiving may challenge the male caregiver’s perception of himself (Harris, 1993). Gender role differences in caregiving are thought to stem from the traditional socialization of children where “girls tend to forge a personal identity based on attachment while boys define themselves through separation” (Kaye & Applegate, 1990, p.10).

Previous research has indicated that men may approach caregiving differently than women (Miller & Cafasso, 1992). Male caregivers take a task-oriented approach to caregiving (Harris, 2002). This approach may help protect them from the stress, feelings of guilt, depression, and anxiety experienced by many female caregivers (Baker et al., 2010). Male caregivers are more likely to use problem-focused coping, while women caregivers are more likely to use emotion-focused coping (Boss, 2011). Some research has suggested that male caregivers may be more effective in suppressing their feelings than their female counterparts, while other studies show few gender differences in caregiving. As the results of research concerning male caregivers are conflicted, it is important not to generalize gender differences in caregiving to all men (Cahill, 2000).

Grief and Loss

Alzheimer’s disease and related dementias are diseases of many continual losses, causing caregivers to repeatedly experience feelings of grief, sadness, and depression (Sanders, Morano, & Corley, 2003). Over time, dementia erases the loved one as the caregiver once knew him or her. Caregivers are steadily exposed to new losses, while still

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trying to make sense of past losses (Boss, 2011). In a 2010 survey, the main losses identified by family caregivers of individuals with dementia were: loss of social interaction, loss over control of life events, loss of well-being, and loss of occupation (Alzheimer's Association, 2013).

Ambiguous loss. Contributing to the grief associated with Alzheimer's disease and related forms of dementia is the idea that the continual decline in the individual's cognitive abilities creates an ambiguous loss. As dementia progresses, the individual is both physically present and psychologically absent at the same time (Boss, 2006). Boss (2011) theorizes that experiencing ambiguous loss is especially traumatic and may be the most stressful kind of loss to family caregivers because the loss remains unclear and does not have the possibility of closure.

Anticipatory grief. Grief reactions may begin in caregivers shortly after a loved one's diagnosis with dementia. Anticipatory grief is defined as:

The phenomenon encompassing the processes of mourning, coping, interaction, planning, and psychosocial reorganization that are stimulated and begun in part in response to the awareness of the impending loss of a loved one (death) and in the recognition of associated losses in the past, present, and future. (Holley & Mast, 2009, p.388)

Anticipatory grief creates the same feelings of denial, depression, anger as well as the physical symptoms that are commonly accepted during the grieving process when an individual dies (Alzheimer's Association, 2013). However, for many family caregivers, anticipatory grief may also lead to what is described as disenfranchised grief, defined as

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“grief that persons experience when they incur a loss that cannot be openly acknowledged or socially supported” (Doka, 1989; Hooyman & Kramer, 2006, p.8). Due to societal, familial, or religious stigmas, it may seem inappropriate for the caregiver to experience such intense feelings of grief concerning a person who has not yet died. Clearly, family caregivers experience many losses and grieve for both the psychological death of their loved one, as well as the impending physical death (Holley & Mast, 2009).

Male caregiver grief. Grief can bring about intense mental suffering for male caregivers. One of the main themes that emerges from the literature is that the grief men experience may be more severe than their female caregiver counterparts because “of the complicated emotional reactions they present and their resistance to accessing emotional support” (Sanders, Morano, & Corley, 2003, p.6).

Male caregivers were more prone to anger and were more likely to feel isolated than female caregivers. In describing their caregiving experience, male caregivers listed the following as their top losses: loss of communication, loss of intimacy, loss of activities, loss of relationships with family, loss of social interaction, loss of physical health, loss of mental health, loss of friends, and loss of self (Sanders et. al, 2003).

Male Caregivers and Support Seeking

Previous literature supports the belief that men are generally more reluctant than women to seek assistance from professionals. Seeking help may conflict with the gendered masculine messages men learned regarding self-reliance and control (Addis & Mahalik, 2003). Male caregivers are likely to busy themselves with their profession or isolate themselves as a means of coping (Sanders et. al, 2003). When facing stressful

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events, research suggests that men do not access social support as readily as female caregivers, and use support groups less frequently than their female counterparts (Addis & Mahalik, 2003; Brown, Shu-il, Mitchell, & Province, 2007).

When male caregivers did seek support, they were more likely than female caregivers to seek assistance with tasks such as personal care and household chores, while female caregivers were more likely to find a support group to attend (Cahill, 2000). However, Kaye and Applegate (1990) discussed the idea that men's lower attendance in support groups may be due to a lack of recruitment efforts to find participants more so than an unwillingness to discuss their feelings.

Support Groups as Intervention

Support groups for caregivers of individuals with dementia date back to the 1970's. Today, the national Alzheimer's Association estimates that over 300,000 individuals living with dementia and their caregivers participate in support groups every year (Hornillos & Crespo, 2012; Alzheimer's Association, 2013).

Support groups, sometimes referred to as mutual aid groups, are one of the most widely used and popular interventions with family caregivers (Hornillos & Crespo, 2012). Group work in the social work field may be defined as a developmental model "which places an emphasis on group processes so that the group may become the instrument in which and through which the participating members may benefit, their interpersonal relationships may improve, and the participants may collaborate, improving conditions in their environment" (Lowy, 1982, p. 22).

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Structure and leadership. The general term “support group” is used to describe a number of possible interventions, which vary in size, structure, and goals. Groups may be sponsored by national organizations, local organizations (such as hospitals and church groups), and by private practitioners (Galinsky & Schopler, 1993). Many support groups are led by a professional moderator or facilitator (often a psychologist, social worker, or nurse), though support groups may also be volunteer or peer-led (Kurtz, 2006).

Support groups may have a variety of purposes and goals: support, education, growth, socialization, and self-help (Toseland & Rivas, 2012). Groups may be composed solely of caregivers, or both the caregiver and their relative with dementia may participate together in the same group. Several organizations offer the opportunity for the caregiver and the person they provide care for to attend separate groups that run at the same time. Certain support groups, such as psychoeducational groups, focus on providing education, resources, and increasing caregiver’s skills, while other groups may focus more intently on the emotional aspects of caregiving, such as sharing personal challenges and feelings. Many groups offer a combination of both education and the opportunity for group members to share their experiences (Hornillos & Crespo, 2012).

Groups may have open or closed membership. In open groups, members may enter or leave the group at any time. In closed groups, the membership stays the same (Toseland & Rivas, 2012). Caregiver support groups are generally open by nature. However, closed groups may provide the higher level of safety and intimacy needed for members to more deeply share and explore their feelings (Kauth, 1992). Support groups may meet indefinitely on an on-going basis, or they may meet for a predetermined number of weeks or sessions.

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Group dynamics. Understanding group dynamics is important for facilitators in order to effectively work with groups. Groups move through phases of development “at their own pace, as the goals of the group are based on the needs, aspirations, and capabilities of its members to satisfy these needs” (Lowy, 1982, p.25). Toseland and Rivas (2012) divided group dynamics into four categories: communication and interaction patterns, cohesion, social integration and influence, and group culture. The cohesion between group members develops over time. High levels of cohesion between group members were associated with greater progress toward group goals, more willingness to listen and share feelings, and a greater ability to provide feedback (Toseland & Rivas, 2012).

Benefits. Support groups offer many benefits for participants. Research has indicated that through support group participation, caregivers gain a better understanding of dementia and increase their knowledge of community resources, while connecting with other attendees who are in similar caregiver roles (Golden & Lund, 2009; Hornillos & Crespo, 2012). Support groups can also normalize and validate caregivers' concerns and experiences.

O'Connor (2002) indicated that caregivers found support groups useful in forming an identity as a caregiver, promoting a sense of competence in the responsibilities of caregiving, gaining a better understanding of the use of formal support services, and reducing isolation, while building a community where members felt welcome and understood. The opportunity for caregivers to discuss their caregiving experiences with others reduces emotional distress and leads to an increase in the

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caregivers' feelings of confidence and competence in their caregiver role (Hornillos & Crespo, 2012).

Limitations and challenges. Past research has indicated that caregivers do not always find support groups helpful. Galinsky and Schopler (1993) noted interpersonal conflict between members, lack of participation, inappropriate feedback between members, and confidentiality breaches as potential drawbacks to support group participation. Some caregivers reported that support groups did not provide them with the educational or emotional support they were seeking. Other caregivers shared that support groups increased their emotional stress and contributed to their depression due to a focus on the over-sharing of the negative aspects of caregiving (Golden & Lund, 2009).

Additionally, studies have indicated that ethnic minority caregivers may be less likely to attend a support group because they assume that the most of the attendees will be Caucasian and will not be able to relate to their experiences of culture and caregiving (Golden & Lund, 2009). However, other studies have failed to find differences in the use of formal support between ethnicities (Chow, Auh, Scharlach, Lehning, & Goldstein, 2010).

Men Supporting Men

Support group participation is often influenced by the composition of the group. Harris (2002) suggested that most male caregivers would prefer to talk to other men. The opportunity to build social connections with men going through a similar situation to their own may feel like the most supportive environment (Russell, 2004). While Harris (1993) noted the absence of the female perspective in the lives of male caregivers as a

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loss, the caregivers studied also expressed the need for specialized services for men as “they were uncomfortable discussing issues such as sex, platonic female companionship, the personal hygiene of their wives, and the lack of their housekeeping skills in traditional support groups that are composed mainly of elderly women” (p.553).

Another point to consider is that husbands and adult sons may experience different challenges and have different needs in caregiving. Therefore, it has been suggested that support groups with the most cohesion among its members are made up of individuals who have the same relationship to the individual with dementia (Harris, 2002).

Support Groups and Older Adults

Support group work with older adults generally focuses on making everyday life more pleasurable and meaningful. Previous research indicates that social support helps protect older adults from the stresses of caregiving and helps them adjust to the major life transitions and role changes that caregiving brings (Rapp, Schumaker, Schmidt, Naughton & Anderson, 1998). Benefits that older adults receive from support group participation include: finding a sense of belonging, receiving validation of one's life experiences, and the chance to share in the ups and downs of caregiving with others. Groups also offer older adults the opportunity to learn new information and skills, provide the ability to approach caregiving challenges differently, and allow older adults to both give and receive support (Rizzo & Toseland, 2005).

Despite the many reported benefits of joining a support group, older caregivers may be more resistant to joining a group due to the fear of being stigmatized for needing

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help. Additionally, older adults may have concerns about group confidentiality (Rizzo & Toseland, 2005). Rizzo and Toseland (2005) identified three main barriers to group participation among older adults: practical barriers, therapeutic needs, and disabilities. Practical barriers such as a lack of transportation or easily becoming fatigued may prevent older adults from attending group meetings. Some older adults may be in need of a higher level of individual support than a support group can offer, needs that might be better addressed by attending individual therapy. Additionally, both physical and cognitive impairments may be barriers to group participation for older adults.

The review of past literature highlights unique challenges older male caregivers face in caring for a relative with dementia and in seeking support for their caregiving responsibilities. However, few studies have examined the support group experience of older male caregivers. Using a conceptual framework of small group theory, this study looked to address the following research question: What is the support group experience of older male caregivers in caring for a relative with dementia?

Methods

Research Design

Qualitative methodology was chosen for the present study in order for the researcher to gain a deeper understanding of male caregivers providing care for a relative with dementia and their support group experiences. Qualitative research was a good fit for the present study because it seeks to understand issues and explore the personal meanings that individuals attach to themselves and their experiences (Monette, Sullivan & DeJong, 2008). Through qualitative research methods, the researcher is looking to

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uncover first-hand knowledge and derive a level of understanding or “*verstehen*” that only an individual living with the experience can offer (Padgett, 2008).

Research participants were asked a series of qualitative questions during an interview that invited the male caregivers to discuss their personal experience of caring for a relative with dementia, as well as share their experience of attending a memory loss support group for caregivers. Questions for this research study were developed after conducting a review of previous literature on dementia caregiving, male caregivers, and the use of a support group as an intervention in meeting the demands of caregiving. The interview was guided by a series of semi-structured, primarily open-ended questions. It was anticipated that the interviews would take approximately one hour to complete. The actual interviews ranged in length from thirty-five minutes to one hour and eleven minutes.

The interview questions for this study were divided into two categories: background information and caregiving and support group questions (see Appendix A). Prior to conducting any interviews, the research questions were reviewed by the researcher, the researcher's paper committee, peer-reviewed by the researcher's classmates, and ultimately reviewed by the University of St. Thomas Institutional Review Board (IRB).

The participants' responses to the interview questions helped the researcher better understand each caregiver's unique experience and were intended to assist the researcher in identifying ways the social work profession might better understand the use of group support in order to meet the needs of the older male caregiver.

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Sample

Five male caregivers were successfully recruited to participate in this study. Participants for this study were male caregivers who currently provide or recently provided care for a relative with dementia and who had also previously attended at least two caregiver support group meetings.

The five male caregivers interviewed for this study all described themselves as Caucasian and ranged in age from 58 to 82 ($M=74.4$). Though questions related to educational background and work histories were not specifically asked by the researcher, this information was revealed in the stories participants shared. The participants held a variety of professional level positions. Three of the participants disclosed the attainment of advanced degrees. All but one participant reported being retired.

Four of the five participants provided care to their wives, while one participant provided care for his mother. The care recipients ranged in age from 71 to 91 ($M=74.8$). Of the five study participants, three had provided care for relatives with Alzheimer's disease, one with dementia with Lewy bodies, and one with Parkinson's disease with memory loss. Three of the study participants currently have the relative they provide care for living at home with them. Two study participants shared their experience of relatives that had eventually been placed in memory care facilities. Two of the participants have experienced the death of the person they provided care for. However, these participants continue to attend a memory loss support group following the loss of their loved one.

At the time of the interviews, study participants had been providing care for their relatives between one and a half years to over 14 years. Participants of the present study

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have attended a caregiver support group for between one and 17 years, with 5.8 years being the average length of time. Two of the study participants attend more than one support group a month.

A note regarding participant age. While the goal of the present study was to better understand the support group experience of older male caregivers, the criteria for a participant to be a specific age was dropped in an effort to recruit more study participants. Additionally, it was thought that the support group leaders who facilitated the recruitment of men for this study would not necessarily know or be able to distinguish the actual age of potential participants. However, the present study's sample ultimately did represent "older" men, with the participants ranging in age from their late 50's to their early 80's.

Recruitment Process

Participants were identified through their affiliation with a support group for caregivers of individuals living with dementia or related memory loss. Non-probability, purposive sampling was used to identify potential participants. In purposive sampling, the researcher has some prior knowledge of where to find a sample that meets the purpose of the research study (Monette et. al, 2011). Participants were recruited with the assistance of three agencies that offer caregiver support groups (see Appendix B). Support group leaders facilitated the recruitment of participants for this study. The researcher requested that support group leaders share information about the present study with participants in their group. Facilitators were asked to read a script out loud to the group (see Appendix C) and then leave the study recruitment flyer (see Appendix D) somewhere in the room

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where potential participants could voluntarily access the information if they were interested in contacting the researcher.

Potential participants were instructed to contact the researcher via email or telephone if they were interested in being interviewed for the study. All study participants contacted the researcher via the telephone. In total, the researcher was contacted by eight potential participants for this study. The researcher then followed up by telephone with the potential participants to share more information about the study and to determine the best time/day/meeting place for the interview. Participants were asked to agree to participate in one interview with the researcher, to be completed either in-person or over the telephone. Participants were also asked to agree that the interview would be audio-recorded and that the information they shared could be presented publicly, in a non-identifying way. For various reasons, three male caregivers declined to participate in an interview for the study after contacting the researcher. Five interviews were completed; four interviews were conducted in-person, and one interview was completed over the telephone.

Additionally, upon completion of an in-person or telephone interview, the researcher offered study participants a \$5.00 gift card to the coffee establishment of their choice. Three of the participants declined the gift card.

Data Collection

Protection of human subjects. Protecting participants' safety during this study was of the utmost importance. This research study was conducted under the supervision of Dr. Kendra J. Garrett, Professor of Social Work at St. Catherine University and the

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University of St. Thomas. This study was also approved by the University of St. Thomas Institutional Review Board (IRB).

An informed consent document (see Appendix E) was provided to every participant prior to beginning each interview. Participants were asked to read the consent form and ask the researcher any questions they might have before signing the consent form. The consent form advised participants of the nature of the study, the procedures involved in the study, and noted the voluntary and confidential nature of the study. Participants also received a copy of the consent form for their own records. One participant requested to be interviewed over the telephone. The researcher emailed that participant the informed consent document and the participant emailed a signed copy back to the researcher. Additionally, the researcher assessed each participant's understanding of the research study and procedures before the interview began.

Participants were informed that their decision to participate or not participate in this study was completely voluntary and would have no effect on their relationship with the sponsor of their support group. They were informed that there were no direct benefits to participating in this study. Participants were also notified that though there was minimal risk involved with this study, the possibility existed that discussing caregiving responsibilities or role changes may be uncomfortable or distressing to them at times. The researcher provided participants with the telephone number for the Alzheimer's Association Helpline, a resource that is available 24/7, where participants could speak to a representative who could assist them with questions or concerns about caregiving and provide the participant with additional resources if necessary.

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Confidentiality of data. Maintaining participants' confidentiality was also of primary importance for this study. When potential participants reached out to the researcher to indicate their interest in participating in the study, they had the option of calling the researcher's private cell phone number with a password-protected voicemail or emailing the researcher to a password-protected email account. All participants initially contacted the researcher via telephone.

The records of the present study were kept confidential. This study produced the following records: a digital audio-recorded voice file of each interview, a typed transcript of each interview, and a small amount of written notes taken by the researcher during each interview. During the research process, the researcher kept all participant information, the digital audio-recordings, and typed transcripts saved in a password-protected computer in the researcher's home that only the researcher had access to. Signed consent forms and written notes taken by the researcher were kept in a locked file cabinet located in the researcher's home office.

Once the data analysis was completed, the researcher destroyed all audio-recordings, typed transcripts, and written notes containing personally identifiable information. These records were destroyed no later than May 18, 2015. However, signed consent forms will be retained by the researcher for three years following the completion of this project, as per federal guidelines and will be kept in a locked file cabinet in the researcher's home office.

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Data Analysis

The analysis of qualitative research relies on “the meanings, concepts, definitions, characteristics, metaphors, symbols, and description of things” (Berg, 2007, p.3). After each interview was completed, the data shared by the participant was transcribed verbatim from the audio-recording of the interview into a typed transcript, where potentially identifying information about the study participant was excluded.

After the transcription had been completed, an analysis of the data was conducted by the researcher using grounded theory methodology. In grounded theory, concepts and themes emerge from codes categorized from the raw data during the open coding process (Monette et. al, 2011). These codes were then grouped into categories and themes in order to respond to the overall study research question: What is the support group experience of older male caregivers in caring for a relative with dementia?

Findings

This research study sought to better understand the support group experience of older male caregivers in providing care for a relative with dementia. After interviewing the study participants and transcribing and analyzing the data, many themes emerged. The findings and themes were guided by two major categories: caregiving and caregiver support group experience. In addition, a brief synopsis of what the present study's participants envisioned as an ideal support group is discussed.

Though each study participant had a unique viewpoint to share about both his caregiving experience and his support group experience, four of the five study participants had similar experiences in that they viewed support groups as an overall

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positive experience that they felt offered them a lot of value. One respondent shared a much different experience in that he viewed his support group experience negatively and did not find much value in attending it. When asked by the researcher why he continued to attend a support group, his response was “*I really can't tell you, I really don't know.*”

Caregiving

Caregiving responsibilities. The caregiving responsibilities varied greatly among study participants. For two of the participants who currently provide care for a relative living at home, duties included almost total personal care in terms of toileting, bathing, grooming, assistance with eating and drinking, and administering medications. This is in addition to attending to all household duties and managing the family's finances. As one participant stated: “*There is simply no end to my caregiving duties.*”

Another study participant caring for his wife at home expressed that he had few personal caregiving responsibilities, as his wife was still able to manage her personal cares. He stated that his caregiving duties centered on the household management, managing finances, and providing his wife with reminders to accomplish tasks.

One participant described providing total personal care for his wife for many years until her eventual placement in a memory care facility. Another participant never cared for his relative at home, but provided care for her while she lived in a memory care facility. Upon placement in a facility, these caregivers described their main caregiving responsibilities as frequently visiting with their relative, managing finances, and ensuring that their relative received proper care and treatment from the facility staff.

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Obligation to provide care. When addressing participants' caregiving responsibilities and the circumstances surrounding why they became caregivers, the main theme that emerged was that there was a sense of responsibility to care for their loved one because of the way the person they provided care for once cared for them. There was an obligation or perceived duty to provide care for their relative with dementia. As one participant shared, *"Caregiving hasn't always come easy to me, but I have been open and willing to learn. My wife took care of me for over 50 years of marriage, don't I owe her that back?"*

Men as caregivers. Four of the five study participants expressed that the adjustment to being a caregiver has been difficult, and all five study participants shared the belief that men face unique challenges as caregivers. Some of the challenges expressed by participants were: feeling that as a man they had a lack of communication skills, a lack of nurturing skills, and that they were raised with the cultural expectation and norms that caregiving was, as one participant stated, *"women's work."* Another participant shared:

Our culture doesn't raise us to be caretakers, and the split roles were very clear in the time I grew up. We are supposed to be the warriors and the breadwinners and of course, that has all pretty much gone by the boards now, as there are many more househusbands and the wife works, but not the men from my generation.

In regards to the challenges of being a male caregiver, one participant expressed:

The biggest challenge for me is that I am a man learning to take care of a woman! That sounds foolish and maybe obvious, but for example, I was struggling with

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learning how to take care of my wife's hair and makeup and clothes and all that, because I've always been a man, right? I don't know about that stuff.

Caregiver Challenges

Caregivers face many challenges in caring for a relative with memory loss. Participants made statements that caring for a person with dementia versus another chronic or terminal illnesses has its own unique set of challenges. Specifically, themes surrounding caregiver stress, loneliness, and isolation emerged.

Stress. Caregiving is a demanding and stressful job. Participants expressed the physical and emotional toll that their caregiving duties took on them. As one participant shared, *"Caregiving has been disturbing and painful and challenging, but I have learned so much."* Regarding the stressful nature of caregiving, another participant expressed:

I am very stressed out at the end of the day. She doesn't recognize me anymore and there is no conversation with her anymore because she can't hold any thought long enough. So, there are days when I have nobody to talk to. She can be very difficult to get along with at times. My wife is so attached to me. Sometimes I want to push her away. I won't push her away of course, but I want to say 'geesh, give me some room here.' She will scream when I leave a room. She will say 'who are you' and I will say 'I'm your husband' and she will say 'no, you are not.' Now, that is stress!

Loneliness and isolation. All but one participant described experiencing intense feelings of loneliness due to his loved one's diagnosis and the demands of his caregiving responsibilities. Additionally, three participants expressed that they had reduced contact

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with friends and family and fewer opportunities for social support since taking on their caregiver role. One participant expressed, *“Nobody knows how hard it really is to lose your spouse in front of your eyes, and you can't do anything about it. Total helplessness. It's scary and sad and lonely. The loneliness is one of the worst things.”*

When describing the isolation he has experienced since taking on the caregiver role for his spouse, another participant shared:

The social component of Alzheimer's is that people do not want to be around you. People are nice, people are sympathetic, but they don't really want you around. My wife can't participate in activities anymore. She gets too confused. It becomes stressful for me, too. So, the world is closing in on me more and more every day. There are days when I don't want to do anything anymore. Sometimes, even I sit in a slump. Cancel this event, postpone that other thing. I can't handle anything else. I'm usually a take charge guy and want to get things done, but caring for someone with Alzheimer's really does a number on you.

Caregiver Support Group Experience

Of the five study participants, all but one reported that his overall caregiver support group experience was positive. This participant shared that while he felt there was value for other people in attending a support group, he did not feel that the support group he attended offered him much benefit. The structure of the groups that the study participants are members of will be discussed, as well as support group benefits, challenges, and ultimately what drives the study participants to continue attending group on a regular basis.

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Group Structure

The support groups represented in this study were similar in structure. Groups met in settings such as hospitals, churches, assisted living facilities, and senior centers. Each group was offered once a month for either one or two hours. All groups were on-going, open support groups, where new members could join at any time.

Format. Four of the five study participants described that their group often had a speaker for the first hour, followed by a check-in. One participant shared that his group is only a “talk” group, where guests are not brought in. Another participant described the format of his group as:

The group has a structured format; there's often a speaker for the first hour. Somebody came in and talked about hospice care. Someone else from the county came in to talk about their programs and services. Then the second hour, we sit around a table and go around and have a check in and they say, 'So, how are you doing today'? Then you respond, 'I'm having trouble with this, does anyone have any ideas?' and someone always does.

Group facilitator. All five of the study participants shared that the support groups they attended were led by professional facilitators. Group leaders were primarily social workers, social work students, and nurses. Participants felt that the facilitator's role was to guide the group, keep the group organized, and to keep the group on task, while making sure that all members have the chance to share. Responses were mostly positive regarding the effectiveness of the group leaders. In regards to the facilitators of his group, one participant stated:

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The facilitators have been very good. They are all caring people. When you get into a caregiver support group, most of what's important is what you have to say and what the others have to say, and to share what your problems are. I don't think there is much for a facilitator to do other to keep track of time and keep the group moving. I wouldn't want a facilitator to do much more than that actually.

Mixed Gender Support Groups

Four of the five study participants attended support groups with both men and women as members. One participant attended an all-male caregiver support group. Two of the five participants acknowledged the potential benefit of having all-male caregiver support groups. One participant stated:

I think there is merit to all-male support groups. I think men need an evolutionary experience. Men deal with life challenges differently. We process emotions differently. There are unmet needs for male caregivers, but we can be in a group with women and men and learn from everyone.

However, four of the five study participants felt that women were an integral part of their support group experience and that having a feminine perspective added a lot of value. Additionally, three participants expressed that having women as group members was, in fact, necessary to exploring the emotional aspects of caregiving. As one participant shared:

Men don't show their feelings. They don't want to look weak. They don't get involved as quickly. The women will jump right in and cry and get to the heart of the issue. I will cry during group from time to time, but I feel like the women in

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group opened that door for me. I have multiple degrees. I'm more educated than other men, but I still feel the pressure that I shouldn't cry or show my emotions sometimes. This is a group to get sad, get angry, and get mad. Most men I've seen stay in the anger. Women help move it to sadness. I wouldn't want all women in a group either. Groups need balance.

Caregiver Support Group Benefits

Three of the five study participants described their monthly caregiver support group as an essential part of their lives. The themes that emerged regarding the benefits of attending a caregiver support group were: knowledge and support, safety, connection, sense of community and belonging, and the ability to release, recharge, and leave group with a sense of hope.

Knowledge and support. The need for practical information and education on dementia, memory loss, and caregiving skills from a reputable source, as well as the need for advice and support were cited the most frequently as to why study participants initially joined a support group. As one participant explained:

I just didn't have a clue in the beginning. I knew I was on my own with the caregiving tasks set in front of me. Group was a place where I could come for real, trustworthy, legitimate information. On the Internet, you go to a website and they are trying to sell you a pill or something that they claim will reverse the disease. I just wanted to cut through all that.

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In describing why he initially sought out a support group, another participant stated:

Typically, I man through things, but I was feeling too overwhelmed by her care and too raw emotionally. I just thought I needed to learn something about Alzheimer's and the stages of her disease. I needed a place I could talk about the situation. I thought I'd try it, and I've been going ever since.

Safety. Having the ability to share about their caregiving experiences openly and honestly was an important reason that the study participants sought out a support group. One participant describes it this way, *“Our group has guidelines. Respect other people in the group. Confidentiality. What is said in the room stays in the room. We need that safety to speak freely.”*

Another participant describes why he sought the safety and confidentiality of a support group:

Support group is the one place where I can share things I would not share with my family members and certainly not with my wife. I would never tell her the kind of stress I'm under. I would never want her to know how bad the situation is, not that she could make sense of it anyway. My dad always told me 'it's a great life if you don't weaken.' So that's what I'm trying to do, not to weaken. That's why I walk, that's why I go to group, so I can pour it all out. I can say it there. It's a safe place and they pledge confidentiality and I think we all take that seriously.

Connection. Study participants described the need to connect with other people who were going through the same experiences as they were. This connection was made

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not only through supportive words, but also by physical gestures such as handshakes and hugs. As one participant shared:

I needed someone to talk to that I felt comfortable with. I was looking to find people who had some background in what I was dealing with. I'm a strong believer in 'if you've walked the walk you can talk the talk, but if you haven't walked the walk you can't talk the talk.' Now, there are always some exceptions to this, but generally I think this is true because these are not just cognitive issues that we're talking about. It's the emotional issues. You need people who have gone through it.

Another participant shared his experience:

During one of my first groups, a lady patted me on the back and said that I was doing a good job taking care of my wife. When she touched me, I realized I hadn't felt that kind of connection with anyone in a long time. It was more than just her words of encouragement, it was the physical too...the pats on the back, the hugs after group.

Sense of community and belonging. As mentioned previously in the findings, the study participants experienced intense feelings of loneliness and isolation in their role as caregivers. Being a member of a support group introduced them to a community of people living with similar stories. While most of the study participants did not form friendships with other group members outside of group, one participant has made several long-term friends from his group that he regularly sees outside of group meeting times.

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Regarding the shared experience and community aspects of group, one participant expressed:

As people talk and share their stories, it's not long before someone jumps in and says, 'yes, my experience with that is....' It's what I call the 'a-ha' experience. It is quite popular at these support group meetings. You say 'my goodness that person has been reading my diary and I am not alone in this.' What I've learned about caregivers is that lyrics of our songs may be different, but the melodies are all the same.

Another participant discusses the sense of belonging he has found from his support group:

The community and social aspects of group are excellent. I can't wait to go back and see these other group members, even though I have no other attachment to them. We're not friends outside of this, but the commonality of caring for someone with Alzheimer's and the other dementias is so emotional that we can't help but feel bonded.

Release, recharge, and hope. Four of the five study participants recognized group as a way to release built up emotions, receive support from others, and leave the group with a renewed sense of energy and hope. As one participant shared:

The public talks about PTSD and talks about it with Veterans, how this prolongs their suffering. I think there is trickle down PTSD effect to caregiving. It has some real residuals. If you don't talk it out, you're going to act it out. You'll act out anger or physical symptoms. If one can go to group and really talk it out... and

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every time they do, it takes a thin layer off them. It takes the edge off to make life manageable a little longer.

Another participant expressed the release that he felt by attending his caregiver support group:

I would never give up my support groups. Never. It's because of group that I can summon the energy to care for her. It's how I unload and how I recharge my batteries. It's how I find out that I'm not the only one. I get enough from group to walk out the door feeling like 'I can do this.'

Reasons for Ongoing Support Group Participation

All five participants of the present study have attended their support group for at least one year. As to the value they find in group and as to why the study participants continue attending group on a regular basis, the following themes emerged: self-care, improved caregiving abilities, new role as teacher, and new role as a caregiver support group advocate for other men.

Self-care. Three of the five study participants viewed attending a caregiver support group as an opportunity for self-care. As one participant described, *“support group is ‘me time.’ It’s the one thing I can look forward to and have control over. I don’t have any control over the disease or what’s happening to my wife, but I can go to group every month and I know there will be people ready and willing to listen.”*

Improved caregiving abilities. Four of the five study participants expressed that attending a caregiver support group improved their caregiving abilities. They recognized

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the value of sharing practical caregiving information with other members and how they were able to take information they learned during group and apply it at home. One participant shared:

There was this lady in group... I was having trouble bathing my wife and she said 'you know what? Here's what you do', so I tried it and it actually works better. It doesn't work much better, but it works a little better and those little victories make a big difference in the outcome of my day.

The study participants also acknowledged that the ability to confide in a group and receive emotional support allowed them to be better caregivers. One participant stated:

Can you imagine me cooped up with my wife 24/7 and not have any way to vent my frustrations and share my needs? I know group makes me a better caregiver. I can let go of anything I need to in group. I'm not afraid to say I've cried before in group. This is sad. Alzheimer's is sad. Losing my wife is sad. Not being able to share my experiences would be even sadder.

New role as teacher. For many of the men who participated in this study, the decision to attend a caregiver support group began as a quest to gain information and a greater understanding about dementia, memory loss, and the practical skills of caregiving. However, a theme that emerged was that by continuing to attend group on a regular basis, they found a new purpose in acting as a teacher or guide to newer members who entered group. As one participant explained:

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I think I have a lot to teach new people who are trying to figure out how to make things work. I feel that's kind of my role now...to teach other people the tricks I've learned. People don't have to do the caregiving alone and for a while I think every caregiver thinks they are alone. I do think we're all lonely, but we don't have to be alone.

Another participant shared how he often takes on a teaching role during his group:

I share things I find with other people. I just think I have some wisdom and insight that the lay person doesn't have, especially in regards to the emotional side of the picture. We as human beings are feeling creatures. It's not just cognitive; it's emotional. We all need love, inclusion, and acceptance – it's a basic human need. A lot of the behavior we see is a result of emotional deprivation, and that has an impact on behavior. Men tend to hide our feelings. Big boys don't cry, you know? I want to teach other men that it's okay to share their feelings.

Role as caregiver support group advocate. Three study participants described that because of their connection to a support group and their belief in the power of a group as a means of supporting male caregivers, that they have become advocates out in the community, trying to get other men to attend a caregiver support group for the first time. As one participant explained:

We need to figure out how to get men to attend meetings. Maybe more education needs to be done regarding anonymity. It might help to have men meet one-on-one with a counselor, so they could get a sense of themselves and a sense of their

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issues before joining group. I frequently meet men who are caring for their wives with dementia, and I tell them about this group I go to. I refer them to group, but they don't often show up. I don't think that's atypical.

Another participant shared a similar sentiment:

I often encourage other men go to group, but so far, I haven't had any takers. I think to admit that you need help is a negative thing for a man. I think it's hard for men to drop into a social setting on their own for the first time. Dropping into a brand new social setting where they don't know anyone else is a difficult thing for us. We also don't want to admit that our wives or spouses are like that.

Caregiver Support Group Challenges

While four of the five study participants reported an overall positive support group experience, all participants also expressed challenges and frustrations with their support group experience. Themes regarding support group challenges were: group size, group length and depth, confidentiality, frustrations with group leaders, frustrations with other group members, and the repetitive nature of the education that was presented in group.

Group size. All participants reported that they attended open groups, where new members are welcomed to join in at any time and where there is no commitment required to attend future meetings. For the participants in this study, their monthly support groups ranged in size from three to 25 members. Group size, both groups that were too big and groups that were too small, were of concern to three of the participants. Speaking about the large number of members in his monthly support group, a participant shared:

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For a time, I thought the group got too big. It can be 25 people at times. I think six to eight people is really the max number in order to really dive deep and go into the deeper emotions. It's harder to relate personally to a very large group. I don't remember their names. You can't invest deeply in 25 people, even if you wanted to.

One participant shared his frustration with having a small number of members in his monthly support group, “ *It's a really small group with only three or four other people. Maybe it would be helpful to have more group members, maybe not. It's the same old people with the same old problems time and time again.* ”

Group length and depth. Three study participants expressed frustration that the sharing component of group that they most looked forward to was rarely long enough and because of the lack of time, there was also a lack of depth to the quality of information that members shared. One participant expressed:

An hour is just not enough time for people to say what they need to say. You just can't go real deep with the issues you're facing. In a big group, there really isn't the same value anymore. Every additional person takes away a little more sharing time from someone else.

Confidentiality. While most study participants shared that the idea of being able to speak openly and honestly about their feelings was what initially brought them to a support group, three participants expressed that they had concerns at times and questioned the safety and confidentiality of the group. One participant stated, “*I don't*

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choose to share all that much with other group members. Maybe it's because it's a small town, maybe it's a lack of trust. I'm not sure things will stay confidential."

Frustration with group leader. Three participants stated they had experienced negative interactions and frustrations with a group facilitator. These experiences centered around the facilitator sharing too much personal information, not running group effectively, and not treating members fairly. Regarding a negative experience with one support group facilitator, a participant expressed:

I actually quit one group before because of the leader. It just wasn't that helpful. That group was led by a woman who cared for her husband with Alzheimer's until he died, but she always talked about herself and her husband a whole lot. It felt out of place for her to be so emotional and share so much personal information with us. She also did a poor job keeping group moving and organized. People were talking over one another and interrupting each other a whole lot. I left group feeling angrier than when I walked in most days, so I quit.

In expressing a frustration with unfair treatment from a support group facilitator, one participant shared:

The leader will go ahead and cut me off if I'm talking too much. Most of the time that's okay with me, but sometimes I get angry feeling like I didn't get to say everything I wanted to get out that night. It seems unfair. This one leader would say 'okay {name}, it's not your show.'

Frustration with other group members. Though fellow group members were primarily thought of positively and held in high regard by the participants, several

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participants expressed frustrations with other group members. Specifically, the frustrations shared by the participants were regarding members that talk too much, members that are not good listeners and do not take the group's advice, and members that tend to ruminate about the same topics time and time again. As one participant shared:

There have definitely been other people I haven't liked too much. Some guys have been real arrogant or know it all types, guys who interrupt other people. Some people are very distracting and rude: playing on their phones, opening candies or food wrappers.

When speaking about his frustration with other group members and the repetitive nature of their comments, one participant stated:

Maybe I'm just an oddball, but I don't see how constantly complaining about the same things with the same people makes anything better in your life. I live by the 'if you don't like something, change it philosophy', is that so hard?

Appropriateness of group members. There were two types of members where the study participants questioned their appropriateness for group: new members and members who continue to attend the caregiver support group after the person they provided care for died.

New members. New members were cited several times by study participants as a distraction. Two study participants felt that new members lessened the quality of support group meetings and felt that there should be more appropriate ways to integrate new members into group. As one participant shared:

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The constantly changing people that show up to group is challenging at times.

New members are usually full of distractions. It seems like they are always late or leave early, and then they have to get settled. I know everyone has the right to be there and I want everybody to get the help they need, but like I said, new members are often a distraction. They can 'cheapen' the experience if you will.

Members attending group after their loved one's death. Three study participants questioned the appropriateness of caregivers continuing to attend a caregiver support group after the person they provided care for died. As one participant shared:

I don't know about people who keep coming to group after their spouse or parent has died. I don't think it's that helpful for the rest of us or for them. Why keep living in the past? Their caregiving journey has ended, even though their grief and dealing with the death has just started. The rest of us are still caregivers. I just don't think it is helpful to have these guys stay in group. Start a new chapter and move on in a different type of group.

Another participant shared a similar sentiment:

I think there's a point when group is no longer appropriate for people whose spouses or parents have passed away to keep coming. On the one hand, it's helpful to hear from someone who has been through the death process, but on the other hand, I'm not sure how helpful a caregiver group is for their situation anymore. I believe they have a right to be there for a while, but their grief can be overwhelming. I don't know what the grief will look like when I lose my wife.

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Repetitive education and lack of new information. All participants in this study attended a caregiver support group for at least one year, and many of the study participants have attended a caregiver support group for many more years. Study participants shared their frustration over the repetitive education topics and speakers that group offered. Participants expressed that topics frequently remained the same and there was a lack of new information being shared during group. As one participant shared:

There's the problem of cycling through the same schedule of programs and lectures over and over again. I got the information the first time around, during the first year. I got to where I wanted more of the support and less of the teachings.

Another participant shared a similar sentiment:

I need less and less practical information from the group anymore. I don't need to know any more about Alzheimer's. I've become an unofficial expert on Alzheimer's over the years. My wife is beyond any breakthrough now. Somebody newer to group brought up the idea that they want more education on dementia. Not me, I'm at the point where I need help dealing with the emotional part. The loss is too much to bear some days.

Vision of an Ideal Support Group

In summary of the findings, study participants described their vision of what an ideal caregiver support group would look like. Overall, the participants shared their preference for a small to middle sized, mixed-gender support group, with more time

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allowed for the check-in and sharing component of group allowing the opportunity for more depth.

Participants shared they would like improved decisions made regarding group membership, such as implementing better ways to integrate new members into the group and deciding how long members should be included in group after the person they provided care for dies. Furthermore, participants cited the need for new educational information to be shared with more variety in the topics that are presented. Further implications for social work practice and group work with older male caregivers will be examined in the discussion section.

Discussion

Caregiver support groups play an integral part in assisting family caregivers cope with the demands of caring for a relative with memory loss. Since the 1970's, support groups for caregivers of individuals living with dementia have been a popular intervention used to improve caregiver skills, reduce caregiver stress, improve caregivers' physical and emotional well-being, and improve caregivers' quality of life (Hornillos & Crespo, 2012).

While caregiver support groups are generally held in high regard as a resource, past literature has had inconclusive findings regarding the efficacy of a support group as a caregiver intervention. Hornillos & Crespo (2012) noted that this may be attributed to the lack of a universal definition of "support group" and due to "inadequate methodological approaches in prior research and the lack of an explicit theoretical framework to drive interventions and research designs" (p. 156). However, past research indicates that

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caregivers do have an increased knowledge of community resources and a better understanding of memory loss and the progression of the disease after attending a support group (Golden & Lund, 2009).

The findings of the present research study were compared with the findings of past literature on dementia, male caregivers, caregiving, and caregiver support groups in order to arrive at conclusions that may be useful in future work with older male caregivers providing care for a relative with dementia. Implications for social work practice, future social work research, and policy will be presented towards the end of the discussion. Additionally, strengths and limitations of the present study will be addressed at the end of the discussion.

Caregiving

Caregiving responsibilities. While there is no typical caregiver or care recipient, the participants of the present study described their caregiving responsibilities as routine tasks that are frequently cited in the literature. Caregiving responsibilities are often broken down into two groups: activities of daily living (ADLs) and instrumental activities of daily living (IADLs). The most common ADLs cited in the literature are toileting, bathing, dressing, and grooming. The most common IADLs cited in previous literature include tasks such as medication management, financial management, and overall household management such as shopping, meal preparation, and cleaning (Fillenbaum, 2006). Three of the five study participants at some point during their caregiving career were responsible for managing almost all ADLs and IADL's for the relative he provided care for.

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Obligation to provide care. As the men in the present study attested to, they felt an obligation to reciprocate care for their wives or mother based on the love and care those women provided them with throughout their lives. Four of the participants in this study spoke openly about the love and affection they had for the women they cared for.

Similarly, previous studies have suggested that husbands take on the role as caregiver “as an extension of their marital vows and the constructed, ongoing reciprocity between spouses” (Thompson, 2002; Neufeld & Harrision, 1998). Sons cited commitment and duty as the primary reasons they took on caregiving responsibilities for a parent (Harris, 2002).

Men as caregivers. All five of the present study’s participants agreed that men face unique challenges as caregivers. Previous literature has suggested that men approach caregiving duties differently than women and are more resistant to seeking help with their caregiving responsibilities (Kaye & Applegate, 1990; Kramer, 2000). As Baker, Robertson, & Connelly (2010) describe:

These men may feel that that disclosing an inability to cope with caregiving may imply they are weak, or not ‘man enough’ for the job. This would lead these men to under-report role strain when questioned about the demand of the role. (p. 325)

Addis & Mahalik (2003) suggested that men’s reluctance to ask for assistance stems from “role socialization paradigms that begin with the assumption that men and women learn attitudes and behaviors from cultural values, norms and ideologies about what it means to be men and women” (p. 7). Interestingly, two of the five participants in

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the present study made comments that they did not consider themselves to be “macho” men and thought that this may have contributed to their ability to access support through a group.

While much of the research on the challenges men face as caregivers focuses on theories such as gender norms, masculinity, and role strain, one somewhat simplified explanation that appears to have been overlooked in the literature is the idea presented by a participant of the present study who described that caregiving is more difficult for him because he is a man taking care of a woman. This implies that naturally, a man, based on gender alone may have a harder time understanding and anticipating the needs of a woman.

Caregiver Challenges

Stress. The stress associated with caregiving is well documented in the literature and was reiterated by this study's participants. The physical and emotional manifestations of stress contribute to feelings of caregiver burden and burnout, ultimately making the caregiver role more challenging (Etters et al., 2007, Kim et al., 2011). Additionally, past studies have indicated that as there is a decrease in the care recipients' functional ability, there is an increase in the caregivers' stress levels and need for support (Kramer, 2000).

Though past qualitative studies suggest male caregivers experience less stress and burden than their female counterparts (Kramer, 2000), the findings of the present study illustrate a different picture. Four of the five participants in the present study described their caregiving responsibilities as quite stressful, overwhelming, all consuming, and burdensome.

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Though they did not use the term “ambiguous loss,” two of the present study’s participants described that their stress levels were increased by frustrations of caring for a relative who is physically present, yet emotionally unavailable in the ways they previously were (Boss, 2011).

Loneliness and isolation. By its nature, caregiving is an isolating experience. Most caregiving takes place between two people in the confines of a home environment, away from family and friends. This change in relationship and roles lends itself to a decrease in social support (Russell, 2004). Additionally, as two of the present study’s participants reported, the stigma of Alzheimer’s disease and related dementias may exacerbate a caregiver’s feelings of isolation as friends and family members withdraw.

Caregiver Support Group Experience

Group structure. Consistent with the findings of the present study and a review of past literature, caregiver support groups are often sponsored by large organizations, hospitals, and social service agencies. Hospitals, churches, and community centers are the most common support group sites (Kurtz, 2006).

Format. As all five of the present study participants described, and the literature reinforces, the format of many caregiver support groups is similar. The support group is often an open group, and the meeting is often divided into two sections: education and support. Education is provided to members regarding the disease and strategies for caregivers to overcome challenges. Members then have the opportunity to check-in and discuss their personal situation with the group and receive advice or feedback from the other members (Kurtz, 2006).

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Facilitator. While many descriptions can be found in the literature as to what the role of a support group facilitator is, the general theme is that facilitators act as empathetic listeners, group planners, maintainers, organizers, motivators, and task masters (Haight & Gibson, 2005; Kurtz, 2006). As Toseland and Rivas (2012) describe, “the leader should be a charismatic role model with vision who helps members align their own goals with group and organizational goals” (p.103). Four of the five participants of the present study similarly described their support group leaders as friendly and caring, with a responsibility for leading the group and managing the group’s time.

Naturally, professionals often led caregiver support groups because many groups are affiliated with social service agencies, national organizations, and hospitals where these professionals work. However, groups may also be led by facilitators without a professional background who have had their own personal experience with the disease (Kurtz, 2006). The present study’s participants shared experiences with groups led by professional and non-professional facilitators and expressed positive and negative experiences with both.

Mixed gender support groups. Small group theory and past literature suggests that support groups composed of individuals with the most similarities have a high level of cohesion amongst the members and, therefore, may offer the most benefit to its members (Golden & Lund, 2009). Unlike past literature has suggested, the findings of the present study indicate that male caregivers would, in fact, not prefer to be in an all-male support group. All of the participants strongly expressed that having women as group members provided a necessary emotional component that opened the male caregivers up to being more emotionally expressive.

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Caregiver Support Group Benefits

Benefits

Consistent with the findings of the present study, past literature indicates that support group participation offers a variety of benefits to caregivers including gaining a better understanding of dementia, fostering feelings of universality, reducing feelings of isolation, and contributing to an overall improvement in mood and feelings of control and competence (Golden & Lund, 2009; Hornillos & Crespo, 2011).

Knowledge and support. The need for knowledge and support, especially regarding decision-making, is what prompted the majority of this study's participants to attend a memory loss caregiver support group for the first time. This is congruent with past research that Brown et al. (2007) conducted that indicated:

Major changes in wives' behavior or needs, changes in husbands' needs or abilities, or changing family circumstances constituted a choice point in the lives of the husbands, where old ways of doing things no longer worked and some action was necessary. (p.355)

Connection, sense of community, and belonging. Support groups often provide members with a sense of community where caregivers discover, often for the first time, that they are not alone (Golden & Lund, 2009). As three of the participants of the present study shared, there were times when they felt they were the only person in the world dealing with their situation. Having similar caregiving experiences and challenges opens caregivers up to sharing, which leads to a willingness to listen to advice from other members, fostering a sense of community (Gitterman, 2004).

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Release, recharge, and hope. Most caregiver support groups are built on shared experience and the ability for members to provide mutual aid to one another. It is this concept of mutual aid that “provides groups their energy, drive, and momentum” (Gitterman, 2004, p.99). As two of the present study’s participants described, there were times when their caregiving experiences seemed hopeless. By attending group, participants were able to express and release built up emotions and frustrations and leave with a renewed sense of hope. Yalom (1995) describes this “installation of hope” as central to group work.

Reasons for Ongoing Support Group Participation

Self-care. While the term “self-care” is not described per se in the literature in relation to the ongoing support group participation of male caregivers, three of the study participants made statements to the fact that support group time was “me time.” The present study’s participants viewed attending their support group as a way to take some much needed time for themselves in order to focus on their own needs. These findings are consistent with research by Brown & Chen (2008) that found men “realized the importance of having time for themselves to exercise, rest or keep doctor or dental appointments and described this as being an important component of being able to continue on” (p.846).

Improved caregiving abilities. Four of the five participants of the present study reported that attending a caregiver support group improved their ability to provide care for their relative. This is consistent with the large body of caregiver support group literature that support group membership led to the caregiver’s perceived self-

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improvement in caregiving ability by learning practical skills and improving the ability to problem solve (Hagen & Gallagher, 1997; O'Connor, 2002).

New role as teacher and caregiver support group advocate. Several of the present study's participants described the sense of purpose they found from attending a caregiver support group and having the ability to use their personal experiences to enhance the lives of other group members. This is consistent with previous literature that indicates that male caregivers may be more likely to seek assistance when they believe they will have the chance to eventually reciprocate (Addis & Mahalik, 2003).

Additionally, past literature discusses the need that support group participants often have to receive affection from other members of the group and its relationship to an improvement in self-concept (Haight & Gibson, 2005). Two participants of the present study described the positive feelings they felt when other members thanked them for advice or told them they were "doing a good job" caring for their relative.

Caregiver Support Group Challenges

As one of the present study's participants explicitly shared, support group members do not always have positive group experiences (Golden & Lund, 2009). Echoing some of the experiences shared by the present study's participants, one study on the experience of grief support groups indicated that members had the following negative support group experiences: group did not meet the member's needs or expectations, group added personal stress to the member, groups lacked structure and were disorganized, and groups had poor leadership (Dyregrov, Dyregrov & Johnsen, 2013).

Group size, length, and depth. Group size was a concern for three of the present study's participants who participated in groups they described as both too small and too

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big. Past literature indicates that an ideal group size is between five to seven members, with seven being optimal. It is important to note that the majority of the literature on group size has been in relation to therapy groups and not caregiver support groups per se. As groups get larger, each member has fewer opportunities to participate and less time is focused on each member as an individual (Toseland & Rivas, 2012, Yalom, 2005). However, groups that are too small run the risk of not having enough participation between its members to be beneficial (Yalom, 2005).

Little was found in the literature regarding group length and its relationship to the depth of content that participants shared during group. The frustrations of the present study's participants regarding the length of the group and the effect it had on depth, may, in fact, be more related to group size. Perhaps in an optimal group size of seven members, the present study's participants would feel as if they had enough time to delve into deeper conversations.

Confidentiality. Trust is an essential component in building cohesion between group members (Toseland & Rivas, 2012). While participants of the present study generally viewed their caregiver support group as a safe place to share about their caregiving experiences and their feelings, several participants also acknowledged in the findings that they had concerns about the confidentiality of group. Toseland & Rivas (2012) suggests that group leaders discuss issues of confidentiality on a regular basis with the group.

Certainly, there are aspects of confidentiality that are out of the members' control. Members cannot be sure that the group leader nor the other group members will keep what was shared during group confidential. Additionally, professional support group

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leaders are mandated by law to report potentially harmful situations such as thoughts of self-harm and incidents of suspected neglect, abuse, or fraud of children or vulnerable adults to the proper authorities (Northen, 2004).

Frustration with group leader. The group leader plays an important role in the overall functioning of the group (Ussher, Kirsten, Butow, Sandoval, 2008). Three participants of the present study shared they had experienced negative interactions with a group facilitator, one participant quit attending a group due to his frustration with the leader. This finding is consistent with past literature that states that the actions of the group leader can, in fact, be harmful to the group (Haight & Gibson, 2005).

Frustration with other group members. Participants of the present study shared that their frustration with other group members, specifically new members and members who attend group after their loved one has died, caused some frustration for them and at times, had a negative impact on their overall support group experience.

Ebenstein (2008) noted that new members may indeed bring tension to a group. First, long-term group members may resent that a new member may be caring for a person who is earlier in the disease and, therefore, has fewer caregiving needs. Second, new members may be frightened by the stories of long-term group members and begin to realize what their caregiving future may hold. Frustrations with other group members may lead to a breakdown in the group processes, though past literature in this area has been inconsistent (Toseland & Rivas, 2012).

Repetitive education and lack of new information. In describing their dissatisfaction with a support group, participants in a study published by Usher et al. (2008) expressed that they felt that many group topics presented were “boring” and not

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relevant to them and this, in part, led them to a decision that it was time to move on from their current group. This was consistent with the findings of the present study that the participants felt frustrated with the repetitive information that was shared. After attending group for many years, the present study's participants felt like they had learned all the basic caregiving information they needed and that new information was not regularly being introduced during group.

Implications for Social Work Practice

Support groups may be effective in reducing the need for more expensive professional services and improving both the caregivers' and care recipients' quality of life (Golden & Lund, 2009). Therefore, support group participation will continue to be an important intervention for family caregivers to receive support with their caregiving responsibilities. Findings of this study have important implications for the social work field as well as for group work practice with older male caregivers in providing care for a relative with dementia.

Need to support help-seeking behavior in male caregivers. The present study highlights the need for the social work profession as a whole to embrace and support older male caregivers and encourage them to at least try group support. Ussher et al. (2008) cited that more awareness around what support groups are is needed. Though they found that study participants had an awareness that support groups were known for being beneficial, there was a lack of knowledge concerning what actually occurred during group.

Another consideration for social workers is that after having a negative experience with formal support, caregivers are less likely to try it again (Brown & Chen,

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2008). Social workers can normalize and validate the importance of group fit and encourage male caregivers to try another group or find another means of support. As one of the present study's participants shared, he tried several groups before finding the one that felt right to him.

Additionally, social workers should consider how they approach older male caregivers in suggesting possible interventions, such as a support group. A man may be more receptive to trying a group if approached one-on-one and is personally invited to group (Brown & Chen, 2008). This would also allow the social worker the opportunity to check-in and evaluate the stress levels of the caregiver and normalize the importance of being able to express emotions in a safe environment in order to reduce that stress.

Support group meeting options. When working with older caregivers, it is important to be cognizant of possible limitations that may affect their ability to attend group meetings. These caregivers often have time constraints, issues with mobility, issues related to driving and transportation, and a lack of respite options available for the person they provide care for that must be considered. The possibility for other caregiver support group options should continue to be explored. For example, groups may be conducted over the telephone or online via a computer (Smith, Toseland, Rizzo & Zinoman, 2005). However, it should be noted that three of the five present study's participants did not currently use email as a main form of communication.

Variation in types of groups offered. Social workers need to be open and flexible to how other groups formats may be able to be offered in an agency or out in the community that better support the needs of older male caregivers. Caregiver support groups are generally open in nature. In many ways, the frustrations over group size and

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group membership expressed by the present study's participants would be lessened in a closed group format.

Past research has suggested that closed groups have the following benefits: a greater sense of member cohesion and trust, greater stability in member roles and group norms (Toseland & Rivas, 2012). However, disadvantages of closed groups include decreased access to new information, facilitator boredom, and the loss of group members. This may be especially poignant when working with older adults, as their physical limitations, issues with transportation, or even their own death may result in their inability to attend group (Corey & Corey, 2006; Haight & Gibson, 2005).

Group membership. The composition of group members is very important to the overall functioning of a group. Therefore, evaluating the appropriateness of group members by the group leader should be conducted on an on-going basis. Certainly in an open support group, the leader cannot filter out members, simply because he or she does not know who is walking through the door on any given day. However, support group leaders can remain vigilant and watch for how a new member or a member that still attends after their relative has died may be affecting the other group members and act accordingly. The social worker may, in fact, be able to direct those members to groups that better meet their needs.

Considerations for group leaders.

Self-awareness. Self-awareness is emphasized in both the study and practice of social work. As Toseland and Rivas (2012) describe "a worker's personality, interpersonal style, and preferences for how to lead, all influence how leadership emerges in the group" (p.110). Knowing this, self-awareness is a vital skill for support group

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leaders. Additionally, group leaders need to be aware of how past personal and professional experiences have shaped their ability to lead and be on the lookout for potential biases that may exist.

All social workers are encouraged to identify personal areas of strength, as well as evaluate areas for growth on an on-going basis. Self-awareness is also related to training. Receiving proper training in caregiver support group facilitation is quite important. Group leaders need to have knowledge of dementia, knowledge of resources, and training in group facilitation, especially related to the issues that may arise between group members (Hornillos & Crespo, 2012). This includes engaging in continuing education for the facilitator in order to keep up-to-date with the current information related to dementia, memory loss, and caregiving, and the ongoing use of consultation and supervision.

Facilitator gender. Though whether or not the gender of the facilitator had any effect on the group members was not a topic explored in the present study, engaging more men to join the social work field might be beneficial in supporting male caregivers. Past research has indicated that men may be more willing to address their needs and disclose information more quickly to a male clinician than a female clinician (Powell, 2006).

Implications for Future Research and Policy

Research. The present research study's overarching research question "what is the support group experience of older male caregivers in providing care for a relative with dementia" was broad in scope. The research question for this study was intentionally left broad by the researcher in order to get a sense of the participants' overall support

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group experience. Therefore, the present research study lends itself as a jumping off point for future research.

Future research could focus on a number of specific variables only touched upon in the present study. A small number of ideas for future research include: how the group facilitator's gender effects group participation from male caregivers, how other members effect group participation, the development of friendships between men outside of group, further explorations of men's negative support group experiences, etc. Research efforts could also focus on the specific challenges associated with men's older age and caregiving abilities. For example, does the need for support increase as the caregiver's age increases? Certainly, the caregiver experiences of older caregivers from a variety of ethnicities and diverse groups, such as caregivers that identify as LGBT, need much more attention paid to them.

Additionally, future research consideration could be given to the idea that the present study's participants shared that women provide a necessary emotional component to support groups that male caregivers find beneficial. Conversely, what women find beneficial about having male caregivers as members of the group, if anything, could be explored.

The researcher found older male caregivers to be hesitant to discuss their caregiving responsibilities and support group experiences for this study. As mentioned previously, three male caregivers contacted the researcher to express their initial interest in the study, but ultimately decided not to take part in it.

One potential participant never returned the researcher's calls after leaving the researcher two voicemails, another dropped out to due an upcoming surgery, and the third

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potential participant told the researcher that he was no longer comfortable sharing his experience for this study. Future research may want to employ different research methods for studying older male caregivers such as group observation over a specific period of time or a focus group.

Policy. Regarding implications for social work policy, social workers need to support policies that will assist all caregivers. Continued evaluation and analysis of the financial and healthcare policies currently in place is needed. For caregivers still in the workforce, policies could be explored that offer caregivers flexible scheduling or time off from work without repercussions to attend a group. Efforts to reduce isolation for care recipients and their partners are needed (AARP, 2015).

Strengths and Limitations of the Present Study

Strengths.

Agency recruitment. Certainly the greatest area of strength of the present study was the successful recruitment of three agencies that had access to upwards of 100 potential support groups. This included the possible inclusion of all-male caregiver support groups and support groups for African American caregivers.

Limitations.

Sample. The ability to generalize the findings of the present study is limited by several factors. First, the sample size of this study was quite small. Second, the male caregivers in this study were all Caucasian and between the ages of 58 and 82. Therefore, ethnically diverse caregivers were not represented in this study. A lack of ethnic diversity in support groups is supported by the literature (Golden & Lund, 2009). Though

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the present study did have some diversity in the age, education, career choices, and economic status of the participants, it was primarily a homogenous group.

Participant age. As discussed previously, the decision to drop a specific age from the recruitment criteria also led to the exclusion of a question regarding the male caregiver's age from the interview. This may have been an unfortunate oversight as the researcher did not specifically receive information from the participants that discussed their perception of their age and whether or not they viewed their older age as having an impact on their caregiving abilities.

Recruitment challenges. As noted previously, while there was the potential for the recruitment materials to reach upwards of 100 support groups, the researcher was made aware of an issue with an initial email sent to a large number of support group leaders by one of the agencies that agreed to participate in the study. The study information attached to the email was unable to be opened by the email recipients due to a "corrupted PDF" file.

Once the researcher was made aware of this issue, the agency was contacted, and they promptly sent another follow-up email to support group leaders. However, there was a delay of over a week between the initial email being sent and the researcher's awareness of the problem. This confusion may have led to a reduction in the number of support group facilitators that actually downloaded the study information and shared this information with their support groups.

Researcher bias. It is important to note that the researcher of the present study has experience leading and facilitating memory loss support groups for family caregivers. Researcher biases may occur when the researcher has preconceived ideas or assumptions

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about the subject matter being studied that may influence how the data elicited through interviews is analyzed (Padgett, 2008). In order to minimize bias, the researcher tried to avoid biased interview questions, leaving the possibility open that older male caregivers may have had both positive and negative support group experiences. Additionally, study interview questions were reviewed by the researcher's paper committee members and were also peer reviewed. Member checking, a process where the researcher verifies his or her findings by going back to study participants in order to ensure accuracy, was initially considered as a means to reduce researcher bias for the present study, but was ultimately ruled out to time constraints (Padgett, 2008).

Conclusion

As the number of individuals diagnosed with dementia rises, older male caregivers will increasingly meet the demand for care. The purpose of the present research study was to better understand the experiences of older male caregivers in caring for a relative with dementia and their use of group support.

Consistent with previous literature, the findings of the present study indicate that overall, older male caregivers find the use of a caregiver support group to be beneficial in providing the practical skills and knowledge needed to provide care for a relative with dementia and believe it to be a safe place for emotional support. However, the men interviewed for this study also believe that they face unique challenges as male caregivers and noted that these challenges have led to increased feelings of stress and the need for supportive services to ease the challenges associated with caregiving.

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Appendix A

Study Qualitative Research Questions

Background Information Questions:

- What is your relationship to the relative you provide care for?
- What is your age? What is the age of the relative you provide care for?
- What is your race/ethnicity?
- What type of dementia has your relative been diagnosed with?

Caregiving & Support Group Questions:

- Briefly describe your caregiving responsibilities. How long have you been providing care for your relative?
- Historically, most men were not raised to become caregivers. How has the role of caregiver been for you?
- Do you think men as caregivers face any unique challenges? If yes, what are the challenges?
- What prompted you to attend a caregiver support group for the first time? What were you hoping to gain by joining this group?
- How long have you been a member of this support group? How often do you attend support group meetings?
- Describe the format of your support group (For example, do you have a guest speaker every week, have check-in time, etc).
- Is there a designated leader for your group?

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- Members take on different roles in a group. For example, some members act as teachers, or advice-givers, while other members choose to primarily listen. How would you describe your participation in the group?
- How would you describe your relationship with other group members?
- What is it like when a new member joins the group? Does having a new member change how you share during group?
- Does your group have both men as women as members? If so, what has it been like to be in a mixed support group with men and women? If not, what has your experience of an all male support group been like?
- How do you think attending this group has supported you in your ability to provide care for your relative?
- How would you describe your overall support group experience? What has been the most helpful to you? What would you change?

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Appendix B

Agency Letter of Cooperation

To the Members of the University of St. Thomas IRB,

We have agreed to assist Olivia Tise with her clinical research project by giving her permission to recruit potential study participants from the caregiver support groups run by XXXXXXXXX, as long as the project receives Institutional Review Board approval. We understand Ms. Tise's research project is exploring the support group experience of older male caregivers in providing care for a relative with dementia. We understand that the research will be qualitative in nature and will be audio-recorded.

We understand that no research will be conducted until Ms. Tise has received approval from the University of St. Thomas Institutional Review Board. We understand that the interviews will take approximately one hour and that participants will receive a \$5.00 coffee gift card from Ms. Tise upon completion of the interview. We also understand that this clinical research project will be published and presented in a public forum.

Ms. Tise will make it clear to potential participants that their participation is entirely voluntary, and the information they share with Ms. Tise will only be used for research purposes. In addition, Ms. Tise will make it clear that the participant's decision whether or not to participate in this study will not affect their current or future relations with the support group they attend or any relationship with St. Catherine University and the University of St. Thomas. Also, participants will be notified that the leader of the support group will have no knowledge of their participation in this study.

In the publication and presentation of this study, Ms. Tise will not include information that will make it possible to identify the participant or the agency in any way. Upon completion of the project, Ms. Tise will destroy all audio-recordings, transcripts, and notes containing personally identifiable information.

Ms. Tise will make it clear to potential participants that they are free to refuse to participate in this research project and this will not affect their relationship to our organization in any way.

Sincerely,

Signature and Title

Print Name

Date

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Appendix C

Research Project Introductory Script

(To be read out loud by the support group facilitator at support group meeting)

If you are a male caregiver providing care for a relative with dementia, Olivia Tise, a graduate student in the social work program at St. Catherine University and the University of St. Thomas, invites you to participate in a study about your caregiving responsibilities and your memory loss support group experience. If you have attended at least 2 support group meetings, you may have valuable experience to contribute to this research.

Participants will be asked to complete one interview that is expected to last approximately one hour. Interviews may take place in person or over the telephone. It is anticipated that 8-12 male caregivers will participate in this study. Participants will receive a \$5.00 gift card to the coffee establishment of their choice as a token of appreciation. Your participation in this study is entirely voluntary. Your decision whether or not to participate in this study will not affect your current or future relationship with this support group or the agency that runs this support group. As the facilitator of your support group, I will not have any knowledge of your participation in this study.

I will leave the study participant recruitment flyer here (on a table or desk in the room). Please contact Olivia directly if you are interested in learning more about this study or would like to volunteer. Olivia's contact information is on the study participant recruitment flyer. Thank you!

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Appendix D

Recruitment Flyer

Invitation to Participate in Research Project on the Support Group Experience of Older Male Caregivers

Purpose of the study: You are invited to participate in a research study investigating the support group experience of male caregivers in providing care for a relative with dementia. Sharing your experiences of being a member of a caregiver support group during an interview for this research study will help the social work profession better understand how male caregivers use support groups.

Who may participate in study? Men who are the primary caregiver for a relative diagnosed with dementia and who have attended at least 2 caregiver support group meetings.

What is the interview like? You will be asked questions related to your caregiving and caregiver support group experience. The interview will be audio-recorded. The interview will take approximately one hour and may be completed in-person or over the telephone.

Who is conducting the study? This study is being conducted by Olivia Tise, a graduate student in the School of Social Work Program at the University of St. Thomas and St. Catherine University. This study is being conducted under the supervision of Dr. Kendra Garrett, who is a professor in the School of Social Work.

How will your privacy be protected? Your participation in this study would be entirely voluntary and information that you share would be kept completely confidential, including your name. The stories and information you provide will be used for research purposes only. If you have any questions about your rights as a participant in this study, you may contact the Institutional Review Board through the University of St. Thomas at 651-962-6038.

How do you participate? If interested in being interviewed for this study, please contact Olivia Tise using the contact information below. Interviews will be conducted between late December 2014 and January and February 2015. Your participation would be greatly appreciated!

<p>All participants who complete an in-person or telephone interview will receive a \$5.00 gift card redeemable at a local coffee shop.</p>
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Contact Researcher: Olivia Tise

Phone: XXX-XXX-XXXX

Email: XXXXXXXXX@stthomas.edu

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Appendix E

University of St. Thomas Research Information and Consent Form

The Support Group Experience of Older Male Caregivers in Providing Care for a Relative with Dementia

[IRB # 670708-1]

Introduction:

You are invited to participate in a research study investigating the support group experience of male caregivers in providing care for a relative with dementia. This study is being conducted by Olivia Tise, a graduate student in the School of Social Work Program at the University of St. Thomas and St. Catherine University. This study is being conducted under the supervision of Dr. Kendra J. Garrett, who is a professor in the School of Social Work. You were selected as a possible participant for this research because you are the primary caregiver for a relative living with dementia and you have attended a memory loss caregiver support group for at least two group meetings. Please read this form carefully and ask any questions you may have before agreeing to participate in the study.

Background Information:

The purpose of this study is to explore the support group experience of male caregivers in providing care for a relative with dementia. This research will provide the social work profession with information on older male caregivers' participation in caregiver support groups, as well as ways to better assist male caregivers in their role. Approximately 8-12 people are anticipated to participate in this research.

Procedures:

If you decide to participate in this study, you will be asked to answer 4 brief questions related to background information on you and your relative. You will then be asked 13 questions related to your caregiving responsibilities and experience in attending a memory loss caregiver support group. You will be asked to agree to allow the audio-recording of the interview and allow the information to be presented publicly, in a non-identifying way. The interview will take approximately one hour. Taking your caregiving responsibilities into account, the interview will take place at a mutually agreed upon, private location. Interviews may also be conducted by telephone on a speakerphone, with no one else present other than the researcher. Interviews will be conducted between late December 2014 and January and February 2015.

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Risks and Benefits of Being in the Study:

This study has the risk of making you feel uncomfortable as you tell me about your caregiving responsibilities, owing to the nature of caregiving responsibilities. You may elect not to answer any interview questions that you do not want to answer. Should your feelings become uncomfortable, you may ask to end the interview at any time. Should you wish to process your feelings further, the Alzheimer's Association Helpline can be reached at 1-800-272-3900 (toll-free, 365 days a year, 24 hours a day). You may speak to a representative who can assist you with questions or concerns about caregiving and provide you with additional resources. There are no direct benefits to you for participating in this research.

Compensation:

If you participate in this study, you will receive a \$5.00 gift card redeemable at the coffee establishment of your choice. You will receive the gift card upon the completion of an in-person or telephone interview, even if you decide to end the interview early.

Confidentiality:

This study will produce the following records: a digital audio-recorded voice file of the interview, a typed transcript of the interview, and may produce written notes taken by the researcher during the interview. The records of this study will be kept confidential. In the publication and presentation of this study, I will not include information that will make it possible to identify you in any way. During the research process, I will keep all participant information, the digital audio-recordings and typed transcripts saved in a password-protected computer in my home that only I have access to. Signed consent forms and any written notes taken by me will be kept in a locked file cabinet located in my home office. Once the data analysis is completed, I will destroy all audio-recordings, transcripts, and written notes containing personally identifiable information. These records will be destroyed no later than May 18, 2015. However, signed consent forms will be retained by me for three years following the completion of this project, as per federal guidelines and will be kept in a locked file cabinet in my home office.

Voluntary Nature of the Study:

Your participation in this study is entirely voluntary. Your decision whether or not to participate will not affect your current or future relations with the support group you attend or St. Catherine University or the University of St. Thomas. The leader of your support group will have no knowledge of your participation in this study. If you decide to participate, you are free to withdraw up to one week following the completion of your interview. You may withdraw from the study by calling me at XXX-XXX-XXXX. You may also withdraw from the study by emailing me at XXXXXXXXX@stthomas.edu.

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Should you decide to withdraw from this study, data collected about you will be destroyed and will not be included in the research results.

You will be given a copy of this form to keep for your records and I will keep the consent form you signed.

Contacts and Questions:

My name is Olivia Tise. You may ask me any questions you have now. If you have questions later, please feel free to contact me on my private cellphone at XXX-XXX-XXXX. You may also contact my faculty advisor for this research, Dr. Kendra Garrett, at 651-962-5808. Additionally, you may also contact the University of St. Thomas Institutional Review Board at 651-962-6038 with any questions or concerns.

Statement of Consent:

Your signature indicates that you have read and understood the information provided above, and that your questions have been answered to your satisfaction. Even after signing this form, you may withdraw from the study up to one week following the completion of your interview and the information you provided will not be used.

I am over the age of 18 and consent to participate in this study. I also agree to the audio-recording of my interview.

Signature of Study Participant

Date

Print Name of Study Participant

Signature of Researcher (Olivia Tise)

Date