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Support groups for Alzheimer’s caregivers: Creating our own space in uncertain times

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Abstract

Older men are often excluded from family caregiving research despite the steady increase in the number of husbands assuming primary caregiving roles. We explored perceptions of older, male caregivers’ experiences with caring for a wife with Alzheimer’s Disease (AD) and examined what aspects of the support group were beneficial. Our qualitative research methods invited six caregivers ranging in age from 74 to 85 years to narratively construct their perspectives on caring for their wives with Alzheimer’s Disease and benefits of participation in an all-male support group. Thematic analyses revealed care-givers faced several transitions. “Losses related to their personal relationships with their wife, family, and self,” captured as loss of golden years. The second area, benefits and improvements of support groups, were captured in the following theme: “creating our own space,” which included two sub-themes: “releasing our frustration” and “developing coping strategies.” There was also “Gendered experience of caregiving.” This study revealed that male caregivers benefited from the support and company of other men in similar caregiving situations. Results from this study have implications for health care professionals for the development of psychosocial educational groups aimed at providing support to male caregivers.

Keywords

Dementia; elderly male caregivers; golden years; husbands; male caregivers support group; older adults; respite; support groups

Introduction

Over the past decades, an overwhelming majority of family caregiving research has focused primarily on the experience of women and has excluded male caregivers (Kramer &

Lambert, 1999). While the majority of caregivers are women, men are steadily increasing in this role (Sharma, Chakrabarti, & Grover, 2016). Men are becoming more involved in informal caregiving due to rapid cultural shifts, changes in social norms, and a more egalitarian society (Hounde, 2001). It is projected that the number of husbands and sons assuming primary caregiving roles for chronically ill older adults will increase, as it is estimated that 74.9 million aging baby-boomers are living longer and with more chronic diseases (The National Alliance for Caregiving (NAC) and Association of American Retired Persons (AARP), 2015).

Despite the increasing emergence of men as caregivers and their differing approach to caregiving, scientific inquiries into their experiences have continued to be fewer than those of their female counterparts. Studies conducted in the United States indicated that women were predominantly serving as caregivers; however, between 20% and 33% of the informal caregivers of the elderly were men (Sharma et al., 2016). According to AARP, “40 percent of family caregivers of adults are men—which equates to 16 million male family caregivers in the United States” (Accius, 2017, p. 1). Male family caregivers have often found their needs underserved and unmet (Kramer & Thompson, 2002). In addition, their crucial contributions to family caregiving and their reliance on formal support services have gone unrecognized (Kaye, 2002).

The growing caregiving role among men suggest they will become consumers of caregiving services (Kaye, 2002; Parker, Call, Dunkle & Vaitkus, 2002), including reliance on formal social support groups for assistance with their caregiving responsibilities. Minimal studies have looked at formal support groups from the perspective of gender, especially the intersectionality of age and gender. Men aged 65 and over are a vulnerable group of caregivers as they have been dependent on their wives for emotional support (Russell, 2001).

There are some inconsistencies in the literature as to whether males need gender homogeneity, an all-male group membership, to meet their needs (Kaye, 2002). McFarland and Sanders (2000) suggest all male support groups are preferable because males are not comfortable sharing their emotional experiences in mixed groups and females tend to dominate discussion. Research does not conclusively demonstrate male only support groups are necessary to provide helpful support. Furthermore, little is known about the caregiving experiences of older, male caregivers. The purpose of this qualitative descriptive study was twofold: 1) explore male caregivers’ perceptions of their caregiving roles, and 2) explore male caregivers’ perceptions of a support group—specifically, what aspects of the support group were beneficial and what improvements are needed to make the support group more useful.

Review of literature

Prevalence of Alzheimer’s Disease (AD)

According to the World Health Organization (WHO) (2016), Alzheimer’s disease (AD) is a chronic and degenerative brain disease that involves deterioration in emotional control, appropriate social engagement, and personal motivation. It is the most common cause of dementia. Dementia is defined as a decline in memory, language, problem-solving, and other

cognitive skills (WHO, 2016). This decline occurs as a result of damage to neurons in parts of the brain that control cognitive functioning, resulting in the inability to perform daily tasks and activities. In AD, the damage and destruction of neurons eventually effect other parts of the brain, including those that enable a person to carry out basic bodily functions such as swallowing and walking. In the final stages of the disease, people are often bed-bound and require 24 hours per day of supervision and care. AD is considered to be a terminal illness (Alzheimer's Association, 2016).

Male spousal caregiving

AD caregiving is defined as providing unpaid care to an individual diagnosed with AD, typically a family member or friend (Alzheimer's Association, 2016). Responsibilities include assisting the care recipient with financial and legal affairs, along with basic activities of daily living (ADLs), (e.g., bathing, dressing, and eating) as AD advances (Cutler & Sramek, 1996; National Institute on Aging, 2006). AD caregivers provide eighty-three (83%) of the assistance need by older adults and about one in three caregivers (34%) are age 65 years and older (Alzheimer's Association, 2016). Approximately 10 million Americans are AD caregivers.

Although only 6% of AD caregivers report caring for a spouse (NAC/AARP, 2015) and the number of male caregivers yields to the female majority, a research focus on male caregivers is warranted. Gerontologists forecast an increase in the number of male caregivers, a group vulnerable to the effects of caregiving burden given their shorter life expectancies and greater health maladies (Fuller-Jonap & Haley, 1995). The challenges of male spousal caregiving are notably distinct. Studies have shown that, compared to their female, spousal caregiver counterparts, males are more likely to report higher levels of fear, to perceive most caregiving activities as burdensome, and to display greater symptoms of burnout, including emotional exhaustion (Hubbell & Hubbell, 2002; Zodikoff, 2007).

AD literature relies heavily on aspects perceived as negative or burdensome; however, male differentiation on caregiving outcomes is not necessarily adverse. Shanks-McElroy and Strobino (2001) reported better physical health and fewer than expected physical health symptoms among male caregivers. Adams, Aranda, Kemp, and Takagi (2002) reported a higher degree of positive caregiving appraisal, and lesser degree of pessimistic appraisal, among male caregivers. Tweedy and Guarnaccia (2007) reported a longitudinal decrease in depression for males following their spouses' deaths (females showed an increase). A significant issue for service professionals is promotion of service utilization that may increase these positive appraisals and benefits for male caregivers.

Gender differences in caregiving such as role expectations, stress levels, coping strategies, and access to and the use of social supports need to be better understood in order to provide the most effective support and services to male caregivers. Gender specific differences in the provision of care for those with dementia or physical illnesses have been found to exist in several areas including time spent on caregiving; the duration of caregiving; types of tasks; role-strain and role-conflict; caregiver-burden; satisfaction with caregiving; and reasons for providing care (Sharma et al., 2016). The literature has found that husbands and wives mostly performed the same caregiving tasks with the same basic feelings and level of

commitment. However, there are still continued differences in caregiving approaches based on the lived experiences of men and women over the life course (Calasanti & King, 2007).

In earlier studies, caregiving was perceived as more negative or burdensome for men than women. It was believed that male caregivers who are caring for their spouses experience notably distinct challenges as compared to their female, spousal caregiver counterparts. Men were more likely to display greater symptoms of burnout and emotional exhaustion, report higher levels of fear, and perceive most caregiving activities as burdensome (Hubbell & Hubbell, 2002; Zodikoff, 2007). However, male differentiation on caregiving outcomes is not necessarily adverse. Shanks-McElroy and Strobino (2001) reported better physical health and fewer than expected physical health symptoms among male caregivers. Other studies have produced conflicting findings, reporting that women may experience slightly higher levels of burden, depression and impaired health than men, with evidence suggesting that these differences arise because female caregivers tend to spend more time caregiving, take on more caregiving tasks, and are more likely to care for someone with a greater number of behavioral problems (Alzheimer's Association, 2016).

Service utilization

Only one-third of eligible caregivers, with awareness of available formal social support, take advantage of these services, and they rarely do so until a crisis emerges (Montgomery & Borgatta, 1989). Spousal caregivers are less likely to have back-up support than other caregivers (Canadian Study of Health & Aging Working Group, 1994). This lack of support points to the need for service utilization among caregivers. Men's experiences of help-seeking for a spouse with dementia differ from those of women (Brown, Chen, Mitchell, & Province, 2007; Calasanti & King, 2007). Male caregivers report a lower level of confidence in the human service system, and are less inclined to seek out community services (Hubbell & Hubbell, 2002; Zodikoff, 2007).

Although there are various community resources available to AD care-givers, the caregiver support group has been shown to be one of the most beneficial. Support groups promote supportive communication and interactions by bringing caregivers together who are experiencing similar challenges, barriers as well as successes. Group members are able to establish nurturing bonds between members and to establish informal supports among each other (Tise, 2015; Martindale-Adams, Nichols, Burns, & Malone, 2002). Caregiver support groups help members learn better stress management techniques, how to access community resources, and how to decrease or even alleviate isolation (Bank, Rubert, Eisdorfer, & Czaja, 2006; Raybuck, 1995). A major obstacle in linking this service to male caregivers is their reluctance to participate in the group process due to a lack of confidence in its effectiveness. They sometimes believe that men do not participate in these groups and that there are no male mentors available to them. And again, there is the perception that participating in "talk groups" implies weakness and a loss of control (Tise, 2015; Kaye & Applegate, 1993). However, there are some indications that men's limited participation in support groups may be due to a lack of recruitment and out-reach efforts by service providers to find participants more so than an unwillingness of men to discuss their feelings (Tise, 2015).

Researching the complexities of male spousal caregiving enhances the knowledge available to gerontologists and other human service professionals, as they attempt to overcome barriers and link these caregivers to support services. Fuller-Jonap and Haley (1995) captured this sentiment: “Although men are the minority of in the total number of caregivers, special problems and needs warrant continued effort to include them in future studies” (p. 116).

Purpose of the study

The gendered experiences of men remain marginalized; particularly elderly men are seldom mentioned in the caregiving literature. There continues to be a lack of research recognizing elderly men are gendered beings, having unique needs and experiences within the caregiving role (Kaye & Applegate, 1994). The gendered experiences of elderly men merit ongoing and expanded examination, especially with greater consideration given to how they perceive and utilize caregiving services. By building on existing research, the purpose of this qualitative descriptive study was to examine the perceptions of male caregivers of wives with AD and their perspective about how support groups were beneficial and what improvements are needed to make the support groups more useful.

Method

To capture their lived experience a phenomenological perspective approach was used. Our qualitative research methods invited men to narratively construct their perspectives on caring for their wives with AD and benefits of participation in an all-male support group. We address the following grand question in this article: How would you describe your experience as the primary caregiver to your wife?

Sample

In qualitative research, purposive sampling is selecting individuals or sites that maximize or minimize differences. Male caregivers who were participants in a male support group at a local, adult day health service organization in the north-western United States was selected as the agency for drawing a sample in an effort to obtain male caregivers who were caring for an older adult with some form of dementia and engaged in an ongoing support group.

To ensure the anonymity of support group participants, a pseudo acronym (MGLCR) is used to represent the name of this organization. MGLCR is a non-profit agency that provides community-based programs targeted toward elderly and/or disabled adults. The range of services includes care management, skilled nursing, occupational therapy, medication monitoring/management, support groups, and respite services. This organization was purposively selected as the agency for drawing a sample in an effort to obtain males who met defined criteria for the study: (a) caregivers—defined as assuming all or most of the care recipient’s needs; (b) active support group participants in an all-male support group at MGLCR—attended the support group within the last six months. After obtaining approval from the director of the agency and University Institutional Review Board, the research team (MSW students and an Assistant Professor) conducted a formal presentation to the male

support group on the intent and purpose of the study. The support group consisted of 6 spouses, who all agreed to be part of the research study.

Participants' profile

The sample consisted of 6 spouses who self-identified as primary caregivers at some point during their wives' progression with AD. All participants were Caucasian and ranged in age from 74 to 85 years old. Most caregivers were married ($n = 5$) and one was widowed, but remained an active participant in the support group. All of the caregivers reported their spouse currently lived in their home and they generally spent greater than 40 hours a week providing care. The amount of time spouses had provided care to their wives ranged from 1 to 5 years. Care recipients ages ranged from 70 to 89 years of age.

A majority of caregivers ($n = 4$) were referred to the support group through the local chapter of the Alzheimer's Association; and the remaining learned about the support group from a friend or relative. All participants reported attending the support group for at least 6 months. Participants were also asked about what in-home services they utilized to support them in their caregiving. Services included Meals on Wheels, chore services/personal care aid, and skilled nursing services.

Data collection

The research team consisted of three Caucasian, female, social work students and one African-American, Assistant Professor female, who developed a semi-structured interview guide which was developed based on the current literature and expanded upon to gain greater understanding about male spouses' perceptions of caregiving. The interview guide started with the grand question, "Can you describe your experience as the primary caregiver to your wife?" and several follow-up sub-areas: a) socio-demographic data (i.e., age, education, income level, relationship to care recipient, length of caregiving, residence of care recipient, amount of time providing care, length of time attending support group); b) being a caregiver (i.e., level of involvement and activities performed, caregiving areas that posed challenges); c) seeking formalized support group (i.e., what factors lead to seeking formalized support group, does support group meet their expectations); and d) perceptions of male caregiver support group (i.e., aspects of support group that was beneficial, application of information learned from support groups, improvements needed to make the support group more useful).

Each caregiver was engaged in a one, face-to-face meeting with two members from the research team. Prior to data collection, the principal investigator practiced with students qualitative interviewing techniques and applications, to ensure there was consistency in addressing various types of probes and questioning styles. Interviews lasted between 1.5 to 2 hours and were conducted in various locations including the organization (MCLCR), a community clubhouse, a public library, and a social service organization. Participants signed written consent forms before interviews commenced. All interviews were audio-taped and transcribed.

Each interviewer created an audit trail by recording notes about the interview to ensure dependability and trustworthiness of the data. The primary researcher, the Assistant

Professor, audited each transcription to ensure consistency across interviewees in transcribing data accurately, to capture emotional intonations in the voices of male caregivers. Although each caregiver was interviewed one time, the wealth of information was in-depth and resulted in a range of 90 to 150 page transcripts, singled space, which is equivalent to about 15 to 20 pages per interview.

Data analysis

Thematic analysis as described by Braun and Clarke (2006) guided data analysis, beginning with the research team reading the transcripts, field notes, and developing a common set of categories and codes. Following, each code and category was compared across for commonalities and differences in their perception of the data. Differences in perception of the data was examined and reexamined, followed with consultation from a trained, qualitative researcher. The research team consisted of a principal investigator and two research assistants. Each independently assigned applicable units of data (e.g., stories, text, comments) to a list of codes to capture the meaning of the text, which subsequently led to a list of relevant codes. The research team met bi-weekly to further analyze participants' transcripts and refine the coding schema. Themes that reached consensus among researchers were grouped into thematic classifications, which represent feelings, attitudes, and experiences of male caregivers.

Results

The results were divided based on two main purposes of the study. The first area, caregivers' perceptions of experience, was captured in the following themes and sub-themes (see Table 1). The primary theme, *loss of golden years* included three sub-themes: *loss of wife*, *loss of family and friends*, and *loss of self*. The second area, benefits and improvements of support groups, was captured in the theme *creating our own space*, and included two sub-themes: *releasing our frustration and developing coping strategies*; and *gendered experience of caregiving*.

Loss of golden years

This theme represented caregivers' experience of multiple losses that occurred while caring for their wives. Captured into three sub-themes are thoughts, feelings, and attitudes about being a caregiver and transitions they faced managing their caregiving role, which were as follows: a) loss of golden years, b) loss of family and friends, c) loss of self.

Loss of golden years captured caregivers' perceptions of how emotional, physical, behavioral, and cognitive changes that occurred in their wife's health erased personal and intimate memories, as well as, created uncertainty around/in their retirement years.

Accordingly, caregiver Y states:

Why in the hell should I be doing what I'm doing, you know? I should be living the golden years of my life now and I'm, it's a terrible word to say but saddled with taking care of somebody and I don't think it's, it's not nice, it's not good. But life must go on, right?

Additionally, caregivers described the loss of the social and emotional aspects of their marriage such as entertainment activities, companionship, and mutual emotional support which was best captured in Caregiver C's narrative:

Well with my circumstances, I've been married 58 years, uh, a very beautiful 58 years. We've held hands and laughed and had fun. All of it, no fights, no nothing, just laughing it off instead of fighting about it. And with the change that starting to come over her, well, it's been hard on me to uh, to get myself to realize she can't help what she's doing and how she acts. I'm very frustrated, we lost our sense of humor which we always had, all our years. I take everything too seriously that she comes up with now, because I'm so wrapped up in trying to take care of her.

Caregivers' experiences such as aforementioned described reveal how AD took away memories, changed relationship interactions and created uncertainty. As the disease progresses, memory decreases, and even the closest family member is no longer recognized: "[S]he got to where she didn't know me and, and I was a strange man in the house and she would panic ..." states Caregiver Z.

Loss of friends and family represents caregivers' experiences of being isolated by friends and family, who no longer visited due to wife's deteriorating condition. Caregiver X's excerpt below best represents the collective voice of the caregivers.

Well as time, as it got worse, it just became harder and harder ... I was so confined as she was. Our friends quit coming around uh quit calling, they don't know how to handle it [wife's condition]. I guess they didn't know what to say. Even neighbors that would stop by or stop and talk to us would just go by and wave. So there is a certain amount of isolation. Our own kids, son and daughter, didn't come around much and I think the kids felt uncomfortable around her. And uh, so a lot of it is... feelings of isolation ...

Further, caregivers described how family and friends' avoidance of wife resulted in a lack of support with managing their caregiving role as illustrated by Caregiver Y's statement:

My difficulty is no support! I have the kids and I've told em, "give us a call once in a while, stop in on your way home from work, stop in and grab a cookie, say hello and leave. But stop, just stop to see us in a while." But they don't! The one son, the youngest one, you know I call him and say "hey, can you give me a hand with ..." They respond, "we've got plans, we've got stuff to do." and that's what I hear all the time. But what I hear all the time is "well, you know let us know when you want something done." I say, "yeah, sure but you know, you're always too busy." So I just hire, if I have something to do that I can't do, I just hire it and forget it ... that's the way it has to be done, so ...

Sharing similar sentiments, Caregiver X adds as follows: "Our own kids ... didn't come around—much ..." He goes on to say, "[I]t's the feeling of isolation." And Caregiver X goes on to say, "A lot of my wife's friends and our neighbors, they aren't very close, they kinda, uh, they kinda, uh, shy away."

When family and friends stopped coming by to visit, male caregivers felt abandoned and isolated from needed support.

Loss of self depicts caregivers' experiences with losing one's self in the role of caregiving. Caregivers described how wives' deteriorating health increased their caregiving responsibilities as it required that they totally focus all of their time and energy in keeping their wives safe. They shared how meeting their care recipients' needs, often left them with minimal to no time for meeting their own physical and emotional needs. Their caregiving responsibilities and demands disconnected male caregivers from their community. For instance, Caregiver X became so involved in taking care of his wife he declared, "I was as confined as she was." Others gave up hobbies and who they were in order to devote all their attention and time to caregiving as illustrated in Caregiver B's narrative:

... In the last couple of years, I use to be able to enjoy doing things like playing golf and at the present time, I don't even feel like I can leave the house for any length of time because I don't know what she is going to do ... I mean it used to be the first couple of years, it wasn't too bad. But then, last two years, it's getting worse. I don't even spend time down in my basement, my computer or my workshop either one of them. I haven't used the workshop for a long time. I'll go to the store and that's about it

Loss of self represented how caregivers viewed changes in wife's cognition and behavior, coupled with isolation from family and friends, meant they spent more time caring for their wife and less time focused on their own self. Despite these multiple losses, most caregivers described how placing their wife in a nursing home facility was not an option as they still held onto memories of what their wife was like before the disease: "because of the closeness we've had all these years, I can't let myself believe I will ever get to the place where I have to put my wife out of the house, you know ..." (Caregiver X). He further states, "women seem to handle it [caregiving] a little better as a rule than men ... women sometimes give up the caregiving sooner, men are stubborn and uh, will bring up this until death do us part thing all the time." All male caregivers perceived that it was easier for women to ask for help or place spouse in facility when necessary, whereas men will care for their wives beyond this point, even if it kills them.

Loss of self was inevitable as caregivers described being preoccupied with their wife's illness which was marked by constant preoccupation with the disease and its effect on their wife's behavior. Safety of their spouses was a priority for the caregivers and they took necessary measures to keep their loved ones from harm. For example, Caregiver Z declared, "I had to take and lock the doors and then she couldn't get out and then she felt like I was turning against her, I think that's when it, that's when it kind of got rough." Another caregiver said he doesn't get much sleep at night because he often gets up to keep his wife safe. According to Caregiver A, "I have to get up at night with her ... she's unsteady on her feet ... so you have, um, makes sure she gets to the bathroom alright and um, back ... tuck her in bed because she might not have the covers over her."

Creating our own space

This theme represented caregivers' perceptions of the importance of a male support group in their lives and how it met their caregiving needs. More importantly, *creating our own space* represented caregivers' belief that a male-only support group created a community where men felt comfortable to share their true feelings about the caregiving process. This need to create their own space occurred when the director requested from a male volunteer, who had previous caregiving experience, to start a male support group due to a male client discomfort in participating in a female-dominated caregiver group. Participants described how it was more comfortable and easier to share with their own gender and voiced the need for more male caregiving groups because they were not as comfortable attending "mixed" gender groups as stated by Caregiver Z, "I think it's kind of a special group, say compared to a ... mixed group both men and women ... well I know, I would be a little bit more hesitant about saying this or that." When describing the process of choosing a caregiver support group, caregiver Y said, "... they gave me a list of support groups and I saw this one, men only, and I thought, well that's something I can handle."

Males described how having a male support group allowed them to define, share, and critique their caregiving experiences as they see it rather than how others view male caregivers. The need to create a space for their shared lived experience is voiced by Caregiver Z, "I could say things, uh talk about, or bring to discussions in more detail than I'd even talk with my kids ... by the same token I had that group feeling of maybe helping others." He further voiced as follows:

Before your spouse got ill, they wanted you to look out for yourself ... biggest barrier ... most men are not about to go out and cry on someone's shoulder ... your friends and all don't really know how to help, so you're not getting that support and so you tend to stay into your shell.

Echoing similar feelings, Caregiver B states, "I can see where I was back here and I can see where I am gonna be heading tomorrow ...". Further, Caregiver A adds that the male caregiver support group helps one, ... get more insight ... a picture of what to expect." Excerpts above revealed that the male caregivers support group provided them a safe place centered around their caregiving experience where they felt more comfortable to share what they were going through.

In this forum of shared space, caregivers noted how attending a male support group served as an incentive for seeking out respite care for their wife. It helped move them from *losing one's self in the role of caregiving* to connecting to community support and resources. As explained by Caregiver C:

It is important for male caregivers to get respite from their caregiving ... it's two hours for me to get out of the house ... you come away from it [support group] feeling better than you did when you came in and it's just, 100% important.

Releasing Our Frustration.—Caregivers felt an all-male support group provided a space for them to openly share their feelings of frustration with managing their caregiving role and coping strategies on managing intense feelings, such as losing their temper. Caregivers were

used to their wives being the nurturer and now they had to take on this role. Caring for their wife, day in and day out, was an exhaustive and frustrating process at times and became to what amounted as a full-time job as illustrated in Caregiver C's excerpt:

I'm doing everything now ... she doesn't do anything. Mornings are almost impossible to get along. From the time she gets up until noon or sometime up to that, she is absolutely difficult. She complains about everything. She acts like everything hurts her, she says "owh" a million times. I get up and do everything. I cook breakfast, do the housecleaning and wash everything. I'm pretty frustrated.

Releasing their feelings of sorrow and frustration in a safe space was important for their well-being. They voiced learning coping strategies for managing their caregiving role. Caregiver Z explained, "[Y]ou can get it off your chest ... during group reducing frustration and anger before going home." Caregiver Y shared, "I've learned patience and tolerance," and Caregiver Z added to this by saying, "[Y]ou roll with the punch, you don't fight it ..." when he spoke about the effect AD had on his wife. Caregivers said they all learned some skill to take with them. To sum it up, Caregiver A said, "... [A]ccepting uh a change that wasn't there yesterday that's there today and once I learned that tomorrow's going to be different than today and just accepting and go with it ..."

In conclusion, creating our own space, gave male caregivers permission to be less preoccupied with their wives' condition. As noted earlier, caregivers became so focused in the role of caring for their wife that they became enmeshed as one. Caregiver Z explains, "You lock yourself into a shell, for protection and you've got to break out of your shell ... the support group really kinda keeps you out of your shell ..." An all-male support group provided them a safe, nonjudgmental space to express strong, intense feelings, such as anger and frustration. More importantly, they learned coping skills to manage their caregiving roles. In what follows are suggestions support group members reported for improving group process and their perspective about gender issues surrounding caregiving.

Suggested Improvements for Support Group.—Some of the male caregivers suggested group sessions are increased to twice a month and to bring more professionals to educate members about recent medicines and medical advances related to AD. All the men expressed the lack of consistency in group facilitators including the facilitator ability to control group members so everyone has a time to talk and check in. Caregiver Y stated, "The only thing I would change is if we could have someone steady all the time." The consistency of having the same facilitator was frequently brought up as was increasing group meetings to more than once a month.

Gendered Experience of Caregiving.—Participants shared their perception of differences between male and female caregivers. Caregiver X states, "... women seem to handle it a little better as a rule than men ... women sometimes give up the caregiver sooner, men are stubborn and uh, will bring up this "until death do us part" thing all the time." Here he is talking about the ability of women to ask for help or place spouse in facility when necessary, whereas men will care for their wives beyond this point, even if it kills them. Caregiver B shares, "... females you know they've been taking care of their family for years ... that's something you have to get yourself used to ..." Male caregivers view their

positions differently from women caregivers. “A man takes his caregiving role as a job and you don’t quit a job, whereas, women see their job as nurturing ...” states Caregiver C. He viewed women as being able to place their spouse in a facility earlier than men. Men will hang in there almost to the end, even at the expense of their own health.

Limitations of study

The results of this study should be interpreted cautiously as there are several limitations. First, the purposeful sampling technique resulted in homogenous sample of older, white, heterosexual, males who lived in an urban area. Therefore, findings from this study may not be applicable to males from diverse backgrounds, such as ethnicity, socioeconomic status, age, race, region, and sexuality. Second, this sample of male caregivers were taken from one support group, which was associated with Alzheimer’s Association, and findings may not apply to those who are not involved in a support group or receiving support from a different organization. Third, all of the male caregivers were caring for a wife with dementia related illness. Thus, issues and concerns that males have when they are caring for a wife who has cancer or another type of chronic illness may be different than what was demonstrated in this study.

Discussion

This study gives the male perspective of caregiving from a population that has been understudied (Kramer & Lambert, 1999), older males. The participants were men caring for, or who have cared for, a wife with AD. They had insightful perceptions of what a male caregiver goes through, needs, and feels about being a caregiver, and the important role support group plays in their lives.

Findings from this study were similar to the current scholarship on male caregivers in that they endure many losses including the loss of community which isolates them even more (Sanders, 2007; Sanders, Morano, & Corley, 2003). Male participants repeatedly stated that family and friends quit coming around, leaving them isolated to care for their wife alone. Another contributor to social isolation may be the caregiver’s reluctance to leave his wife alone (Harris, 1993; Siriopoulos, Brown, & Wright, 1999). Men tend to lose social connectedness and become isolated (Kramer & Thompson, 2002).

This study reinforced the belief that elderly men often have little or no experience with the tasks associated with caregiving responsibilities (Kramer & Thompson, 2002), yet are taking on the role of primary caregiving. These male caregivers view of doing what they need to do and making the best of it shows the commitment to their loved one. This also supports the results of earlier studies that have demonstrated that many males have successfully taken on the task of caregiving and generally fare quite well (Cahill, 2000; Russell, 2001; Sanders & McFarland, 2002). An earlier caregiving study revealed males became caregivers primarily out of a sense of duty and were not as committed or emotionally attached to their loved ones (Harris, 1993). This is contrary to what was found in this study. All the male caregivers acclaimed deep commitment and were emotionally attached to their loved ones. In addition to love, a few brought up the “til death doth us part” marriage vows as a base for commitment which concurs with findings of previous research (Kramer & Lambert, 1999; Kramer &

Thompson, 2002). Participants in this study agreed with the literature in that men perceived caring for a family member as a job (Kramer & Thompson, 2002). It is difficult for men to “quit” caregiving and put their wife in a facility when needed, which can result in frustration and loss of self.

Due to the losses and isolation caregivers stressed the importance and impact support group had on their lives. Male caregivers in the current study reached out to other group members by sharing their caregiving experiences. In the literature, the majority of males reported feeling “very comfortable” sharing experiences in the support group they attended (Kaye & Applegate, 1993). Researchers have also found males utilized support groups for respite which provided them the opportunity to share with others (Archer & MacLean, 1994). This study revealed that male caregivers need the support and company of other men in similar caregiving situations. Recent literature states that the power of support groups is derived from the supportive bond and cohesion that develops between members who are experiencing similar situations (McFarland & Sanders, 2000).

It became apparent early on that male caregivers have a lot to say and want to be heard. Male caregivers have the insight and strength to enlighten the caregiving definition. Participants reported the most beneficial aspects of the support group were being around individuals with similar experiences and having emotional support of other males.

Implications for social workers and healthcare professionals

Findings from this study will lend to the development of psychosocial educational groups aimed at male caregivers. Recognizing the importance of an all-male support group and what is needed to create a safe community for sharing intense and often times, uncomfortable feelings and experiences are critical for their overall well-being. Social workers and healthcare professionals will need to provide grief counseling and support around issues of loss males often experience in their caregiving roles. The gender and age of caregivers are relevant in assessing their strengths and needs. In this study, caregivers ranged in age from 74 to 85 years, which suggests that caring for a loved one with dementia related illnesses or chronic health conditions can place a heavy burden on the physical strengths and stamina of older caregivers. Developing a plan that would include community and family resources for addressing issues of isolation and loneliness in their caregiving role is important for their well-being (Vakalahi, Simpson, & Giunta, 2014). Finally, educators should recognize the need for expanding gerontology content in curricula, especially focusing on dementia and other chronic conditions that require long-term care.

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Table 1.

Main themes regarding support groups for Alzheimer’s caregivers.

Caregivers’ Perceptions of Experience: Loss of golden years

Theme 1: loss of wife

Theme 2: loss of family and friends

Theme 3: loss of self

Benefits and Improvements of Support Groups: Creating our own space

Theme 1: releasing our frustration

Theme 2: gendered experience of caregiving

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