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Relationship Between Stress Burden and Perceived Support Among Elderly Male Spousal Caregivers

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MSN, Seton Hall University, 1985

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Doctoral Study Submitted in Partial Fulfillment

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Abstract

As older couples age, often one partner becomes more competent and able to care for the other, in which case they are able to remain in their homes. In one township in the northeastern United States, the caregiving role had a significant effect on the lives of elderly men who care for their wives. The purpose of this quantitative project study was to determine the relationship between perceived stress burden and perceived level of social support services and between perceived stress burden and use of support services by elderly male spousal caregivers residing in active adult communities. Watson’s theory of caring provided the theoretical foundation for this study. A correlational design was used and data were collected from 82 elderly male spousal caregivers with (a) the Zarit Burden Interview; (b) the Multidimensional Scale of Perceived Social Support; and (c) a checklist, Support Services in Your Area. Descriptive analysis indicated that participants carry a large stress burden, particularly emotional stress (Zarit Burden score of 36.58/65), enjoy strong social support (Multidimensional Scale score of 45.47/75), and use few community services. Pearson’s product-moment correlation revealed no significant relationship between perceived stress burden and perceived social support or between perceived stress burden and use of community services, indicating that men feel emotional stress but the feelings are not related to their use of community services. As community services were not used by elderly male caregiver spouses, a workshop for professionals was developed to help the professionals expand programs and services that may have value for these men in their caregiver role. This study has social significance because satisfaction with the caregiver role has consequences for the health and financial. well-being of the elderly and for U.S. society.

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Section 1: The Problem

Elderly men are more likely to be married and live with a spouse than are elderly women (U.S. Department of Health and Human Services, 2012) but both men and women are equally likely to have conditions in their older years that affect their ability to perform activities of daily living. Older men are as likely as older women to take on a caregiving role for an impaired spouse. According to American Association of Retired Persons (AARP, 2009), one third of elderly caregivers are men. Many elderly male spousal caregivers (EMSCs) must adjust lifelong habits and learn new skills to accommodate their new role of household manager and care provider in what was once a marital partnership of shared responsibility and support. EMSCs are increasing in number (U.S. Department of Health and Human Services, 2012). Determining what supports that these men need to fulfill their caretaker role with equanimity may improve their lives and the lives of their care-recipient wives.

The Local Problem

In a rural community in the northeastern United States are eight age-restricted active adult communities composed of approximately 14,000 adults older than 65 years ([Redacted] Township Home Page, 2013). The number of caregivers is large enough to support three distinct caregiver support groups within the township. There is an Alzheimer’s support group facilitated by social workers at a university physician practice, a general caregiver support group coordinated by Jewish Family Service, and a spousal caregivers group under the auspices of a large university hospital. A counselor for the

Office on Aging at the study site estimated that 60% of her time with clients is devoted to finding ways to alleviate clients' felt burden of caregiving (personal communication, November 15, 2012).

I facilitate the monthly spousal caregiver support group meetings, which typically has six participants each month. In my own practice as a geriatric nurse practitioner in this community, I regularly find devoted EMSCs who struggle with the day-to-day tasks that evolve from a developing caregiver role in the home due to the wife's continuing illness. Spousal caregivers have shared that they feel isolated and do not fit in with elderly singles. Married couples with whom they would feel more connected, however, prefer to socialize with healthy couples and frequently neglect to include caregiver/care-recipient dyads. One caregiver equated her status as a caregiver to being "a half widow," not accepted into single or married social groups (personal communication, March, 2011). One of the EMSCs in my support group stated that his children are wonderful, caring and concerned but the truth is "they cannot understand the problem of caring for their mother because they do not fully see the disability" (personal communication, 2013).

One EMSC is keeping his wife's request to keep her dementia a family secret, while learning meal preparation, a task he had not undertaken prior to her memory failure (personal communication, August 2012). A major caregiver concern expressed among my clients is the isolation that develops when caregivers and their care-recipient spouses become marginalized within the community. Because of the low participation in support services by EMSCs noted by a counselor for the Office on Aging at the study site (personal communication, November 15, 2012), men's particular needs are overlooked; no data on EMSCs are collected or compiled by community support agencies.

Initiation into the role of caregiver is unplanned and disorganized, occurring as health and functional changes transform a spouse into a care recipient. Caregivers are unprepared for their new role and EMSCs may be even less prepared than female caregivers are, given traditional division of breadwinning and caregiving duties within the family, particularly in this generation that is now elderly. In my experience as a spousal support group facilitator, men appear to be less willing than women to participate in caregiver support groups, possibly causing EMSCs to be at greater risk than women for physical and emotional problems. The attendance rosters of the support seminars show that EMSCs participate less consistently in caregiver support groups than elderly female caregivers do. In the active adult community in the northeastern United States, the focus of this study, research has not determined the needs and concerns of EMSCs.

Rationale

Feinberg, Reinhard, Houser, and Choula (2011) noted that those who take on the caregiver role to help loved ones remain in their own homes risk stress, depression, physical health problems, social isolation, competing demands, and financial hardship and that the caregiver may become vulnerable themselves. Feinberg et al. estimated that the value of this unpaid care at home reached $450 billion in 2009, which is a 21% increase since 2007.

The United States Census Bureau (2010) predicted that in the next 2 decades, the proportion of people 65 years and older will climb from 13% of the total U.S. population to 19%. The number of men older than 65 years will more than double from 2010 to 2050 (U.S. Census Bureau, 2010). This large population of male aging baby boomers suggests an increased need to examine caregiving relationships and ways to support all caregivers for the good of not only care recipients but also caregivers themselves.

Male caregivers are one third of the caregiving population (Naiditch & Weber-Raley, 2009); their unique needs are not well documented compared with those of female caregivers. Knutsen and Raholm (2009), for example, noted that “there appears to be little understanding of the ways men experience and manage the strain of caregiving” (p. 50). This gap is understandable; informal caregivers are more likely to be female because women typically live 5 to 6 years longer than men (Kirkwood, 2010). Researchers in several studies examined the role of the female caregiver and caregiver stress (Cao et al., 2010; Pihl, Fridlund, & Martensson, 2010; Pioli, 2010; Savundranayagam & Montgomery, 2010; Takai, Takahashi, Iwamitsu, Oishi, & Miyaoka, 2011), but, as Weinland (2009) pointed out, little information is available about the specific needs of the male spousal caregiver. Weinland’s interviews of African American male caregivers concluded that agency personnel tended to apply a one-size-fits-all approach that may not meet the needs of men or people of color. Calasanti and King (2007), Knutsen and Raholm, and Sanders and Power (2009) conducted qualitative studies of small numbers of men and found that husbands’ experience of transition into a caregiving role is different from the experience of wives. They concluded that little understanding exists of the caregiving experience of elderly men. A study by Ski and O’Connell (2007) concluded that caregivers risk physical and emotional problems when caregiving at home.

In the United States, approximately 44 million American families and friends provide voluntary care to another adult and, according to the Family Caregiver Alliance (2013), provide approximately 80% of long-term care that is delivered within the home. AARP is an organization that has members older than 50 years and the organization works to encourage progressive social change for individuals as they age (AARP, 2013). Authors of an AARP study (2009) estimated that there were 43.5 million caregivers of persons aged 50 or older in the United States.

EMSCs who live in a rural community in the northeastern United States are the focus of this study. The average age in this 42-square-mile community is 53.2 years. The target township has the largest number of adults older than 65 years in its county, according to the [Redacted] County Office on Aging 2010 census data information. The target community has a larger elderly population than many surrounding municipalities due to the eight age-restricted communities located within the township, representing 14,000 adults older than 55 years. According to the U.S. Census Bureau (2010), the proportion of the target state’s population classified as elderly is expected to increase from 13.7% in 1995 to 17.3% in 2025. This increase is due to the aging of the baby boomers and may create more caregiver/care-recipient households.

This anticipated increase in the number of elderly and in the number of elderly who will require daily assistance by a spouse provides the rationale for this study. An evaluation of social and professional support for men thrust into the caregiver role late in life is of value to the caregiver/care-recipient dyad and to the community, because it might aid in reducing caregivers' physical and emotional stress and perhaps the cost of care.

Unlike the current study, previous studies have targeted situations in which the care recipient was diagnosed with a specific disabling condition. For example, spousal care of someone with Alzheimer's disease was the focus of studies by Knutsen and Raholm (2009);Sussman and Regehr (2009); and Valimaki, Vehvilainen-Julkunen, Pietila, and Pirttila (2009). Brazil, Thabane, Foster, and Bedard (2009) studied Canadian couples affected by terminal illness but less than one third of the caregivers in this study were men. Pihl, Fridlund, and Martensson (2010) and Rohrbaugh, Mehl, Shoham, Reilly, and Ewy (2008) both concentrated on couples in which the care-recipient was being treated for heart failure. Rodrigue et al. (2010) examined the experiences of those caring for older kidney transplant patients. Sanders and Power (2009) did not restrict participants to a particular disabling condition but focused on dementia and other chronic conditions. In this quantitative project study, my focus was on male spousal caregivers who live in an active adult community where the caregiver and spouse reside together.

As Aneshensel, Pearlin, and Schuler (1993) noted, caregiving is a role that no one imagines will be part of his or her future. The informal caregiver, regardless of sex, must assume roles that may be unfamiliar to him or her. Role expectations that may be unfamiliar for the male caregiver spouse include cooking, cleaning, shopping for food and clothing, caring for pets, making appointments, gardening, and staying in contact with primary family members, because these activities are often performed by wives, especially in older, more traditional couples. The marital roles in a home with a disabled spouse evolve in ways that are unexpected by both caregiver and care-recipient, and for which neither is prepared.

Several researchers have described these feelings of disorganization and strain. Pinquart and Sorenson (2011) found that “spousal caregivers report more depressive symptoms and greater physical and financial burden than adult children caregivers” (p. 7). Tamayo, Broxson, Munsell, and Cohen (2010) found that caregivers feel isolated and overwhelmed by home maintenance tasks and also by administering medications and monitoring side effects. Either one of these task domains is difficult enough to manage; the combination of two domains presented simultaneously can be a strain (Levesque, Ducharme, Zarit, Lachance, and Giroux, 2008). However, as Weinland (2009) found, the majority of EMSCs do not make use of available community services. Men try to soldier on without help.

The purpose of this quantitative project study was to determine the relationship between stress burden and level of social support, and use of support services by EMSCs residing in active adult communities in the northeastern United States. The study goal was to determine what assistance and education can be provided to improve their lives.

This study has the potential to help the EMSC by providing clues to educational services that support organizations may provide.

Definitions

For the purpose of this quantitative project study the following terms are conceptually and operationally defined:

Activities of daily living: Activities of daily living include toileting, feeding, grooming, ambulation, dressing, transferring and bathing (Katz, 1983).

Active adult community: Active adult communities include apartment complexes and houses that offer no assistance with daily living activities but usually offer a variety of on-site activities and easy access to natural or cultural attractions. Active adult communities encourage active and healthy aging and convey feelings of belonging (McHugh & Larson-Keagy, 2005).

Elderly adult: Many developed countries have recognized the chronological age of 65 years as a definition of elderly person (World Health Organization, 2014). As benchmarks in the literature use the age of 60 (ADP Research Institute, 2013) and because active adult communities admit residents younger than 65 years, this study will use the age of 60 years and older.

Informal caregiver: An individual who acts as a support person for the ill patient; typical examples include a spouse/partner, other relative or friend who provides physical and or emotional support (Abernethy, Burns, Wheeler, & Currow, 2009).

Instrumental activities of daily living: Instrumental activities of daily living include the use of the telephone, shopping, laundry, and transportation, management of food preparation, medication, housekeeping, and finances (Lawton & Brody, 1969).

Professional caregiver: Mental health workers, hospice nurses, or social workers who have specialized skills and are paid to care for adults in need of assistance (Haigler, Bauer, & Travis, 2004).

Social support: A social network or relationship provided by others with measurement of that support based on the report of perception by the recipient (Cukrowicz, Franzese, Thorp, Cheavens, & Lynch, 2008).

Male spousal caregiver: A male spouse who resides at home with his wife and identifies himself as a caregiver (Hawranik & Strain, 2007).

Significance

The task of giving care to a chronically-ill spouse can change the balance of a happy marriage, leaving the caregiver isolated in this new role. A couple older than 65 years facing a persistent health problem of one partner can see their quality of life change, for the caregiver and for the care recipient. A chronic illness is often the cause by which a care-recipient is moved into a care facility. From both a social and a financial perspective, such a move can be devastating for an elderly couple, which increases pressure on the caregiver spouse to persist in caregiving at home despite the stress and social impact of this role.

In a 2012 survey of 2,250 adults aged 60 years and older by the National Council on Aging, in conjunction with United Healthcare and *USA Today* (2012), researchers found that 90% of seniors plan to stay in their own homes after retirement. Many seniors want to stay in the home they like and they desire to stay close to friends and family. But the reality is that life experience changes in the face of a debilitating illness, especially for the caregiver. The need of the caregiver to provide quality care, in addition to performing household tasks that were once the province of the ill spouse and to maintaining his own health as aging affects him too, can upend life satisfaction (Marsh, Kersel, Havill, & Sleigh, 1998). One EMSC reported an emotional and physical toll that occurs when caring for a spouse with a chronic illness with no happy ending in sight (J. Taylor, personal communication December 18, 2012). Schulz and Beach (1999) reported that participants who were caregivers had a 63% higher mortality risk during the 5 years of the study than did spouses who were not caregivers.

It is crucial for providers of services to the elderly to know the level of caregiver burden and the perceived support that the male caregiver spouse experiences in the informal caregiver role. These providers need a clear understanding of the needs felt by EMSCs so they can offer education and services to assist the men to adapt to their evolving role of caregiver.

There are multiple businesses, assisted living communities, home care agencies, home maintenance services, and municipal agencies that offer amenities to the many senior citizens who live within this township. The findings of this study and the resulting project have power to alleviate the stress burden of EMSCs and therefore improve quality of life for these men.

The Office on Aging in the township that was the focus of this study is a hub of activity for elderly adults and local agencies. The results of the study provide professionals working in township agencies with insight into the needs of the male caregiver spouse and inspire new service offerings. I developed an educational project (Appendix A) comprised of recommendations for professional practice derived from the results of this study.

Research Questions

This study investigated the following five research questions:

1. What level of stress burden do EMSCs perceive in their caregiving role?
2. What level of social support do EMSC perceive in their caregiving role?
3. What use of community social services do EMSCs report with regards to their caregiving role?
4. What is the relationship between perceived stress burden and perceived social support?

   H_1: A significant relationships exists between perceived stress burden and perceived social support.

   H_0: No significant relationship exists between perceived stress burden and perceived social support.

5. What is the relationship between perceived stress burden and use of community social services?

   H_1: A significant relationships exists between perceived stress burden and use of community social services.

   H_0: No significant relationship exists between perceived stress burden and use of community social services.

Review of the Literature

The purpose of this quantitative study was to provide research based descriptions of the perceived stress burden, social support, availability and usefulness of support services for EMSCs with the goal of determining what assistance and education can be provided to improve their lives. This literature review includes studies that were found using the Walden University online library system to discover articles related to male caregiver spouses. The following databases were searched and articles retrieved from: CINAHL, Google Scholar, Medline, Nursing and Allied Health, Ovid Nursing Journal, Psych Info, Sage, Thoreau, and SocIndex. The keywords used to search the literature were: *aged*; *caregiver burden and strain*; *caregiving*; *caregiving motives*; *caregiving spouse*; *chronic illness*; *community service*; *family caregiving*; *home care service*; *informal caregivers*; *male caregiving spouse*; *older adults*; *older people*; *planned retirement communities*; *qualitative studies*; *quantitative studies*; and *social support*. The literature review begins with a description of the theoretical framework.

Theoretical Framework: Watson’s Caring Theory

This study was based on Watson's Caring Theory (1999), developed as a framework for the professional development of nurses. Since caregiver spouses choose to care for their spouse at home and this decision transforms them into the role of informal caregiver, Watson's ideas are pertinent to this study. Watson and Smith (2002) wrote that "Caring knowledge and practices affect all health, education, and human service practitioners" (p. 455) and this includes the caring role of the caregiver spouse. The practice role of nursing includes helping people cope with problems of daily living that are related to their health problems (California Scope of Practice Act, 2004), and so transcends the boundaries of clinical nursing and fits well the challenges faced by EMSC.

Watson and Foster (2003) believed that each thought and choice that individuals make carries energy into their lives and into the lives of others, so that a care-provider's presence makes a difference for a patient, separate from any medical intervention or supervision, and that caring and compassionate acts of love cause healing for the patient but also for the caregiver. This transpersonal conception of caregiving applies to health professionals but also to informal caregivers, such as spousal caregivers. As partners in the care-recipient/care-provider dyad, both the ill individual and his or her care provider can feel emotional healing and support through the transpersonal nature of the caregiving act. For example, nine male caregiver spouses interviewed by Knutsen and Raholm (2009) noted that caring for their wives was a central role in their lives and that proficiency in that role gave the caregivers a sense of fulfillment and satisfaction. These men said that were proud of their caregiving work and they enjoyed mastering the skills needed to care for their wives.

Watson (2003) identified four components of her caring model, which she called The Four Cs; these are *collaboration, conflict resolution, change management,* and *construction of a new identity*. *Collaboration* is manifest in a caregiver's realization that caring is done with a care recipient, not to her. *Conflict resolution* is a necessary skill because, in the midst of the collaborative nature of caring, differences of opinion about the goals and methods of care inevitably arise between the caregiver and the care recipient, and it is the caregiver's responsibility to resolve this conflict amicably. The condition that led to the need for care inevitably changes the life of the care recipient and the life of the caregiver as well, especially the life of a spousal caregiver, so that *change management* is part of a caregiver's work and includes helping the care recipient adjust to change and accepting a shared life experience that is in many ways diminished at least different from what it was. Finally, Watson (2003) assigned to the caregiver the task of assisting the care recipient in *constructing a new identity* in the face of changes that have occurred and will occur in the future. These changes occur in the life of the caregiver as well, as he or she grows and adjusts to new roles and new realities.

The salience of Watson's Four Cs has been verified in subsequent research (Buyck et al., 2011; Cao et al., 2010; Pihl, Fridlund, & Martensson 2010; Scotto, 2003). Spouses of heart failure patients (Pihl et al.2010) whose main task was to keep the care recipient's disease managed, demonstrated their acceptance of the role of caregiver by making changes in their social life and also by expressing a need for care themselves to adjust to the changes that their spouse’s health had triggered in their own lives. Individuals who assume the role of informal nurse must care for themselves physically and emotionally in addition to being proficient in nursing duties (Scotto). Failure to make these personal adjustments led informal caregivers to report the greatest burden in terms of poor mental and physical health (Buyck et al., 2011). Outside support for the caregiver role is essential for the health and well-being of both the care-recipient and the caregiver (Cao et al., 2010), and this need may be highest among those least familiar with traditional caregiving roles, including male spousal caregivers (Scotto, 2003).

Although Watson’s (2003) caring theory relates to caregiver spouses similarly to its relevance to professional nurses, the caregiver inhabits also the role of one who needs care. The EMSC is unprepared for the functional and emotional burden associated with giving care and for the impact the illness and the need to provide care has on his emotional connection to the care recipient, his wife. The male spousal caregiver is an authentic presence to his spouse and in the dimensional role as a spouse and caregiver hopes to assist the care recipient live her life and their life as a couple to its fullest degree. However, caregiving has no timetable and the responsibilities change dependent on the needs of the care recipient (Savundranayagam, Montgomery, Kosloski, & Little, 2011). The caregiver spouse needs ongoing support and education to improve health outcomes for the care recipient and for him.

To provide the support and care that EMSC need requires an understanding of their situation. The next sections of this review describe the typical life of elderly men who are the focus of this study.

Active Adult Communities

Active adult communities first appeared in the United States in Florida in the 1920s, sponsored by nonprofit organizations in an effort to support their retiring members and others who had been affiliated with their organizations (Hunt, 1984). The industry leader, Del Webb, currently offers 59 active adult communities in 21 states (Del Webb, 2013a). These communities attract seniors who are financially secure and recently retired or even still working (Frankel, 2013). According to Frankel, only approximately 5% of adults aged 55 and older buy homes in active adult communities, but with 78 million baby boomers approaching retirement, this is still a large number and likely to grow.

Active adult communities fall into five distinct types: adults-only towns distinct from neighboring communities; retirement villages within towns housing the general population; retirement subdivisions similar to villages but on a smaller scale; retirement buildings housing active seniors; and continuing care retirement centers offer a range of options from independent living to 24-hour nursing care (Hunt et al., 1984). Each of these variants limits household members by age and promotes itself safer as and more fun than prospective purchasers’ current neighborhoods.

Fun is a key element. Active adult communities promote active leisure which serves as an “antidote to aging and negative stereotypes of older age” (McHugh, 2007, p.

296). Baby boomers are especially attracted to active adult communities because they tend to include all maintenance of the home and property, accommodating floor plans, park areas with attractive landscaping, and a clubhouse with recreation rooms for parties and hobbies, a fitness center, and a pool (Bernstein, Ottenfel, & Witte, 2011). Older adults who choose these communities clearly envision for themselves a life of physical health and much social interaction. They envision them as the proper location for their retirement years.

The target communities in this study are typical of active adult communities generally, which follow guidelines first established in 1995 in the Housing for Older Persons Act of the federal government (Department of Housing and Urban Development, 1999). Rules require that at least one household member be 55 years old or older and that additional household members be at least 48 years old. According to a director of one such community, there have been rifts between community members who have resided within the community for 20 years or more (and so are in their late 70s and 80s) and new younger members who still work (personal communication, S. Brenner, July 22, 2013). New residents in their late 50s and 60s expect programs and lectures to be offered in the evenings to accommodate their working schedule, to the distress of older members who prefer daytime activities. These differences point out the range of experiences within the older adult age group and also the importance of activities in these active adult communities.

Although the Housing for Older Persons Act does not require any amenities or services for elderly residents, active adult communities attract purchasers through activities including golf, tennis, swimming, exercise programs, social events, and a variety of classes (*Chicago Tribune*, 2013). The residents who move into these communities, including those in this study's target area in the northeastern United States, have a desire to keep active and healthy. I myself have seen elderly clients return to the clubhouse just seven days after hip surgery, so important was it to them to resume an active life style.

Participants in my spousal caregivers' support group confirm that the focus in these communities is on high levels of physical and social activity. Some caregiver/care recipient dyads living in an age restricted active adult community may feel marginalized because their need to receive or provide care restricts their ability to be as active as they had planned to be in their retirement years. Feelings of marginalization and restriction may contribute to caregiver stress.

Caregiver Stress

Caregiving, in either a professional or informal role, places caregivers at risk for physical and emotional problems (Aneshensel, Pearlin, Mullan, Zarit, & Whitlach, 1995). Caregiver stress levels are particularly high when the care happens not as part of a job but at home (Creese, Bedard, Brazil, & Chambers, 2008; Duxbury, Higgins, & Smart, 2011; Salin, Kaunonen, & Astedt-Kurki, 2009). Those who care for family members at home cannot escape to a less stressful environment. This is especially true for caregivers who provide care full time, including men who are retired. One study screened 6,806 adults and found a strong negative effect associated with being an informal caregiver, on home life, work responsibilities and on caregivers' own health status (National Alliance for Caregiving in Collaboration AARP, 2009)

Caregivers were found to be more likely to report fair or poor health the longer they had been in their role as a caregiver, according to the National Alliance for Caregiving (2009). This finding of failing health was also reported in a meta-analysis of caregiver stress and health effects (Pinquart & Sorenson, 2006), and among elderly couples in which the care recipient had end-stage kidney disease (Wilson-Genderson, Pruchno, & Cartwright, 2009). Similarly, both male and female caregivers of those afflicted with lung cancer found that caregivers' mental and physical health were lower than population averages (Mosher, Bakas, & Champion, 2013). One third of the caregivers in that study reported adverse physical effects of caregiving, including body pain, emotional upset and decreased vitality. My own experience bears this out. One caregiver in my practice reported that during the years that he cared for his wife, he rarely sought out medical care for himself due to time required to so do and his inability to leave his wife alone (P. Berkowitz, personal communication, 2010).

Social isolation is another problem facing caregivers, who experience the role captivity that leads to limited social engagement (Aneshensel et al., 1993). A study of 49 caregivers in Turkey of those ill with multiple sclerosis found that caregiver exhaustion increased with social isolation (Akkus, 2011). Similar outcomes were found in a study of caregivers for persons with dementia (Andren & Elmstahl, 2008). Male spousal caregivers caring for demented wives feel lonely due to the inability to converse with their wives about the future that they had formerly shared (Knutsen & Raholm, 2009). Feelings of role captivity decreased for elderly caregivers when care-recipients were moved to a nursing home and when the care-recipients' health declined precipitously with institutionalization (Aneshensel et al., 1993). The threat of triggering the death of a spouse by abandoning one's caregiver role seems to epitomize the very notion of role captivity.

Caregiver stress can be alleviated with support. For example, 400 caregivers of spouses afflicted by dementia participated in a program of family counselling sessions, enrollment in a weekly caregiver support group and unlimited counselling by telephone, while a similar number in a control group received information about Alzheimer's disease and assistance upon request but no formal support program (Mittelman, 2002). The caregivers in the treatment group experienced significantly less depression than the caregivers in the control group. Additional studies (Emanuel, Fairclough, Slutsman, & Emanuel, 2000; McDonagh, et al., 2004) of caregivers caring for family members with serious or life threatening illnesses discovered that when caregivers were given the information they seek related to physical care and disease progression, the caregivers experienced less depression and a better quality of life.

Caregivers of elderly spouses are usually older too. Caring for a spouse with a chronic debilitating condition can stress the caregiver to a greater extent than might be felt by a younger family member who is less intimately connected to the care recipient. A caregiver spouse may have physical limitations himself that also add to the burden of caring for his spouse (Family Caregiver Alliance, 2013).

Members of older caregiver/care recipient dyads made the decision in a happier time to live in an adult community. The purchase of their home promised a lifestyle of activity and adventure, as portrayed in promotional materials distributed by at least one developer (Del Webb, 2013). However, drastic lifestyle changes occur when one marital partner falls ill or is no longer able to get around without assistance. These changes contribute to stress, in the infirm partner but also in the partner who suddenly must deliver care. In an ethnographic study of men caring for wives with dementia, Black, Schwartz, Caruso, and Hannum (2008) found that "the isolation of caregiving may lead to increased mental and physical health problems in an aging body and at a time of diminishing resources" (p. 180). This care entails many tasks for which a caregiver, including an elderly male caregiver, may be unprepared, including mastery of new knowledge and skills. The need to learn new things may contribute to caregiver stress.

Stress Related to Knowledge and Skills

Contributing to caregivers' stress level is being unprepared for all that is required in giving care. Caregivers report feeling uninformed about their spouses' disabling conditions, uncertain of their ability to deliver home medical care, incompetent in household tasks their spouse once managed, and unable to foresee their future. A life that once seemed routine is suddenly shaken by these four issues.

Disease management. In a study conducted by Kernisan, Sudore, and Knight (2010), over 1,800 individuals who visited a caregiving website were asked what they most needed to know. The predominant answer was health information and practical caregiving assistance. Respondents reported concern for complex chronic conditions and confusion over what to do to care for someone with such a condition at home (Kernisan, Sudore, & Knight, 2010). This hunger for information is driven by a perceived lack of information from in person doctor visits and other healthcare providers about how to care for a patient at home (Given, Given, & Kozachik, 2001). In fact, caregivers have indicated that after accompanying the care recipient on medical visits, they remained unaware of the type of care required by the care recipient, including how to administer it.

Lack of understanding about medicine and nursing procedures also surfaced as caregiver concerns (Macisaac, Harrison, & Godfrey, 2010; Wakefield, Hayes, Boren, Pak, & Davis, 2012). Understanding better what caregivers need to know about caregiving would be helpful in supporting caregivers in ways that increase care recipients' comfort and effectiveness (Given, Sherwood, & Given, 2008).

Practical nursing skills. Comfort and effectiveness are essential to the health and happiness of the care recipient but caregivers, especially EMSCs, feel intimidated by their lack of proficiency at the tasks expected for caregiving, including personal care for their wives, medication administration and supervising care recipients' therapy (Black et al., 2008; Kernisan et al., 2010). Men in marriages governed by traditional gender roles typically have little experience with child care or other caregiving tasks and habits of mind. Caregivers have indicated they need help with practical nursing skills as well as information on interpreting symptoms and reactions (Kernisan et al., 2010). Participants feel unable to confidently evaluate their care recipient's condition in order to make timely care decisions.

Foreseeing the future. Professional nurses may understand the course of a disease and are alert to changes that signal a new phase of a patient's condition. Lay caregivers often do not. Spousal caregivers are caught up in the present complexity of their situation. They may want to know how their wife's disease will progress but cannot pause in the day-to-day work of giving care to consider this. Knowing what to expect and how to plan for the future is a keen interest of caregivers (Kernisan et al., 2010). However, this lack of knowledge of what the future holds may be difficult for a caregiver spouse to articulate. It is estimated that as many as two thirds of elderly spousal caregivers need more professional support, more respite care and more emotional encouragement in order to manage their caregiving role (Peeters, Van Beek, Meerveld, Spreeuwenberg, & Francke, 2010).

In addition to the stress caused to caregivers by the need to master new knowledge and skills, caregivers may feel stress with regard to the care recipient’s inability to do things independently. This stress is derived both from a need to do more for the care recipient as her abilities diminish and from the emotional toll this diminution exacts on the caregiver.

Stress Due to Activities of Daily Living

Day-to-day care, including feeding, bathing, toileting, and dressing an incapacitated care recipient, is especially poignant and stressful for the caregiver. Elderly men, who may have little experience performing such tasks even for their own children many years before, feel ill-equipped to manage these tasks now for their wives.

The Instrumental Activities of Daily Living (IADL) scale was created to pinpoint caregiving tasks for the infirm elderly (Lawton & Brody, 1969), and was confirmed to be a reliable instrument to measure caregiving tasks associated with everyday life (Piercy, Carter, Mant, & Wade, 2000). IADL scale includes the use of the telephone, shopping, laundry, and transportation, and the management of food preparation, medication, housekeeping, and finances. These skills are necessary life skills, yet married men and women traditionally divide these tasks by their own skill set and are more comfortable completing some tasks more than others. McKinnon (1991) found a traditional divide between “men’s work and women’s work” among Canadian elderly. She notes that, “elderly men are much more likely than elderly women to provide assistance with tasks such as transportation and yard work, while elderly women (usually spouses) are significantly more likely than men to provide assistance for housework, meal preparation, grocery shopping, and personal care" (p. 65). Over a long marriage, many tasks individuals may have felt capable of in their younger days, like laundry, grocery shopping, and doing taxes, fall into disuse as they are delegated to one spouse or the other.

The Activities of Daily Living (ADL) scale (Katz, 1983) is another tool that is widely used today in the clinical area and in a patient's home (Wallace & Shelkey, 2007). In contrast to skills included in the IADL scale, the ADL scale includes more personal tasks of toileting, feeding, grooming, transferring from one location to another, ambulation (including walking, using a walker, and using a scooter or wheelchair), dressing, and bathing. Gender differences are evident in this scale too, in that women are more likely than men to assist a spouse with toilet related tasks, while EMSC were more likely to provide mobility related assistance to their wives (Brazil et al., 2009).

Male spouses often report they never contemplated assisting their wives with ADL and this may increase the felt burden for male caregiver spouses (Calasanti & King, 2007; Sanders & Power, 2009). The role of caregiver has traditionally been a female one and men may feel that admitting an inability to cope with caregiving suggests that they are weak and may lead some men to under-report role strain when questioned about the demands of caregiving (Baker et al., 2010).

Several studies reported that a caregiver's highest level of burden is associated with the care recipient's need for daily help (Dougherty & Thompson, 2009; Garlo, O’Leary, VanNess, & Fried, 2010; Savundranayagam & Montgomery, 2010). This suggests that care recipients’ need for assistance with ADL scales outweighs concern for information regarding disease symptoms in a calculation of caregiver stress. Anticipating the care recipients’ need for assistance with any one of the ADL scales adds to caregivers’ level of anxiety and even negatively impacts caregivers’ sleep (Rowe, Kairalla, & McRae, 2010).

IADL scale (Lawton & Brody, 1969) and ADL scale (Katz, 1983) both measure the functional ability of a care recipient and are predictors of caregiver burden. Although both ADL and IADL are recognized by elderly caregivers and care recipients, it is the personal care routines named in ADL scale that have a greater influence on the strain experienced on the caregiver spouse (Chan & Chui, 2011).

The strain of dealing with everyday tasks is revealed in men’s coping strategies. Calasanti and King (2007) found that EMSCs who were interviewed about their experience managing ADL for wives diagnosed with Alzheimer’s disease coped with caregiving tasks by blocking emotions, distracting themselves, and self-medicating with alcohol and other substances. In another set of interviews, elderly men who provided care for their wives with memory loss and other chronic conditions expressed a desire to maintain their wives’ dignity and utilize services to aid with home care but refused to share their feelings about their own caregiving experience (Sanders & Power, 2009), as if by not discussing their distress they could safely ignore it. Similar issues emerged in a year-long study of EMSC, who were found to demonstrate an increase in psychological distress and a decline in self-perceived health status over time, triggered by struggle with subjective stressors, like feelings of inadequacy, guilt and anxiety (Ducharme, Lévesque, Zarit, Lachance, & Giroux, 2007).

The research clearly points out the complex and pervasive nature of stress felt by EMSCs. Since stress has an effect on physical health, the stress burden felt by EMSCs may cause a decline in their health even as the health of their wives declines.

Stress and the Health of a Caregiver

Caregivers in several studies described a decline in their own personal health (Buyck et al., 2011; Ducharme et al., 2007; Pihl et al., 2010). Such a decline negatively affects both marital partners. If a caregiver's health declines to the point that he or she can no longer give care, the care recipient is in danger of nursing home placement. Male caregiver spouses who were asked who would care for their wives if they themselves became ill admitted that their children were too busy with their own lives and their wives would have to go to a nursing home (Sanders & Power, 2009). The knowledge of his responsibility for his wife's future care places even more pressure on the male spousal caregiver and amplifies the importance of his own health (Sanders & Power, 2009). Yet no research was found demonstrating that male spousal caregivers recognize the consequences of neglecting their own health care while fulfilling their caregiver role.

Depression as a result of caregiving is well documented in several studies (Adams, McClendon, & Smyth, 2008; Buyck et al., 2011; Ducharme et al., 2007). Depression of the caregiver is directly related to "role captivity," which is the feeling of being trapped in a particular role with no way out except through changes that are even worse than the current situation (Ducharme et al., 2007). One gentleman reported exercising once or twice a day just to avoid depression, and others admitted to self-medicating with alcohol to cope with the demands of caregiving (Calasanti & King, 2007). Caregivers with the highest reported burden score described poorer mental and physical health than individuals not caring for an older adult (Buyck et al., 2011). The level of measured burden is correlates to perceived caregiver health, so that caregivers with lower stress burden reported a higher measure of perceived personal health (Andren & Elmstahl, 2008).

Sleep plays an essential role in good health. An adequate supply of quality sleep can help protect mental health, physical health, and well-being (National Heart Lung and Blood Institute, 2014). However, individuals caring for a spouse with Alzheimer’s disease reported poor sleep and were at increased risk for poor mental health (Willette-Murphy, Todero, & Yeaworth, 2006). No sleep differences between caregivers and non-caregivers were found in older women caring for persons with osteoporosis but caregivers who were clinically depressed reported more sleep problems than non-caregivers who were depressed; caregiving represents an added risk to depressive individuals (Kochar, Fredman, Stone, & Cauley, 2007). This is significant because depression is common among elderly caregivers, so the risk of sleep-deprivation and accompanying health problems among caregivers is strong (Kochar et al., 2007).

Caregiving represents an independent risk factor for elderly caregivers (Schulz & Beach, 1999). Elderly who provide support for another and who report role strain are 63% more likely to die within 4 years than those who either are not providing care or who report no strain in the caregiver role. The level of patient suffering may contribute to a decline in the health of the caregiver since working so hard "to provide help that then fails to enhance the quality of a care-recipient's life may lead to frustration, resignation, and negative health effects for the caregiver" (Koerner et al., 2010, p. 110-111). Psychological and physical symptoms in caregivers are more likely on days when care recipients were especially needful and when social supports are absent or perceived negatively (Koerner, Shirai, & Kenyon, 2010).

The potential to positively affect the sleep quality of caregivers of individuals with dementia and reduce their depressive symptom scores can be realized through a treatment program that combined relaxation techniques, control of stress triggers, and education in good sleep habits along with personal goal setting (Simpson & Carter, 2010). But overall, the intensity of caregiver strain can lead to a myriad of negative health effects, including early death of the caregiver. Simpson and Carter suggest that social support is valuable in maintaining a caregiver's mental and physical well-being but that the perceptions of an elderly caregiver about his situation and the situation faced by the marital dyad may be significant. The effect of stress on a married couple may undermine this most intimate form of social support.

Stress and Couple Identity

Older couples typically portray their marriage as having a better marital interaction than younger married couples (Levenson, Carstensen, & Gottman, 1993). Over the course of their marriage, husband and wife often adopt a single couple identity that is more salient even than their individual identities. Couple identity is stronger than biological sex in determining relationship satisfaction (Berg & Upchurch, 2007).

Strong couple identity alleviates feelings of strain and lost companionship directly associated with caregiving and the care recipient’s limitations and also mediates associated feelings of role captivity and limitations on personal freedom (Badr, Acitelli, & Taylor, 2007). Individuals who view their couple’s relationship as integral to their personal identity may experience fewer negatives of the caregiving experience. A strong couple identity may be beneficial for caregivers and contribute to more adaptive caregiver outcomes.

But what happens when this couple identity unravels as illness replaces shared activities and mutual support with worry, endless care, and little hope for the future? Caregivers often experience conflict between feelings of connection to and separation from their spouse, tension between their own needs and the needs of their spouse, and confusion between a sense of knowing the future and at the same time not knowing the future (O’Shaughnessy, Lee, & Lintern, 2010). Caregivers desire more control over their situation even as that control is undermined by the health of the care recipient. As their spouses' health declines, caregivers experience continual re-evaluation and re-positioning of themselves in relation to their partner and to the couple relationship.

A model for caring for those with dementia may be based on the couple relationship. The ability of the spousal caregiver to cope with a care recipient's failing health, either by accepting it or avoiding thinking about it, influences his or her behavior as part of the couple and predisposes the caregiver to interact either authoritatively or equitably in relationship to the care recipient (Piiparinen & Whitlatch, 2011). How the caregiver copes determines how well the couple relationship survives the stress of illness. It is the threat of loss, and how the caregiver responds to that threat, that influences his ability to withstand the emotional impact associated with giving care.

One of the emerging themes in conversations with caregiving husbands is the desire to maintain the relationship (Brown, Chen, Mitchell, & Province, 2007), a sentiment that implies they are not carrying on with it as well as they wish. Men report struggling with grief and loneliness while caring for wives afflicted with dementia (Knutsen & Raholm, 2009). Three factors related to the couple bond had either direct or indirect effects on caregiver depression: the loss of intimate exchange, the present quality of the couple relationship, and a caregiver's perceived loss of self (Adams, McClendon, & Smyth, 2008). These confirm the importance of personal and relational losses in the stress felt by elderly spousal caregivers and point out the need for social and community support.

Support Needs of the Caregiver

Due to the fact that caregiving for a spouse is an unexpected career without an orientation or a position description, many caregivers seek support (Salin, Kaunonen, & Astedt-Kurki, 2009; de Leon Arabit, 2008; Sussman & Regehr, 2009). Nearly all participants feel invigorated by a respite care period (Salin, et al., 2009). The respite care offered in Finland consists of time in an institution for the care recipient (Salin et al., 2009), yet de Leon Arabit found that none of the caregivers in a United States study of caregiver coping strategies sought formal interventions, perhaps because they were unaware of local resources. Spousal caregivers' involvement with community services is poor as well in a Canadian study (Sussman & Regehr, 2009). The caregiver spouses found that with the exception of adult day care, available services did little to reduce their level of stress burden. The lack of perceived value of community-based social services found in these studies suggests that elderly caregivers may look to friends and family for support.

It appears that support from friends and family may also be inadequate. Caregivers of people with Parkinson's disease have reported they undertook this role with minimal information and with little support from family and friends (McLaughlin et al., 2010). In fact, spouses often feel that their caregiving efforts were ignored by friends and family (Pihl et al., 2010). Caregiver spouses feel that their loneliness was increased by their friends' disregard for their needs as a caregiver. Caregivers need encouragement in their caregiver role and social support in order to continue in the role of caregiver (White, D’Abrew, Auret, Graham, & Duggan, 2008). Caregivers with lower social support perceive the role of caregiver as more burdensome (Hwang, Fleischmann, Howie-Esquivel, Stotts, & Dracup, 2011).

Caregiver spouses need information to care for themselves as well as for their wives. Educational programs to support caregivers and assist them with self-care have been described in studies by Elliott, Burgio, and De Coster (2010), White et al. (2008) and Peeters et al. (2010), among others. An intervention group, receiving services under the Resources for Enhancing Alzheimer’s Caregiver Health program, reported reductions in caregiver burden and better self-rated caregiver health at the end of six months (Elliott et al.. A six-week program for caregivers that provided education and support for informal caregivers increased emotional comfort and improved caregiving skills (White et al., 2008). Individuals caring for a spouse with dementia were found to need more emotional support and relief care than caregivers who were sons or daughters of the care recipient (Peeters et al., 2010). Researchers (Elliott, Burgio, & De Coster, 2010; Peeters et al., 2010) have recommended that agencies assess the extent of social support existing for elderly caregivers, which aligns with the focus of my study.

There are numerous studies related to female caregiver spouses but I have identified only seven articles devoted to understanding the male caregiver spouse. This limited research has focused on men’s desire to keep their home lives as normal as possible despite their evolving caregiver role (Sanders & Power, 2009; Black et al., 2008), their struggle to integrate caregiving into traditional attitudes about masculinity

(Baker et al., 2010), and men’s ways of approaching caregiving tasks that differ from the typical approaches of female caregivers (Calasanti & King, 2007). EMSCs were found to become more vulnerable to emotional distress, physical decline, and counter-productive ways of managing stress as their caregiving role extended over time and was recognized by the men to describe a limited future without hope of improvement (Ducharme et al., 2007).

All of these studies stated that existing interventions need to be more inclusive of male caregiver spouses; the development of male support groups, separate from support groups for women or intended for both sexes, may be beneficial. More research and understanding of the plight of the EMSC are needed. Male caregiver spouses are a growing group that needs and deserves more attention.

Implications

The ability of EMSCs to continue to provide care and support for their wives at home depends upon their own continued good health, including mental health. Yet men’s reluctance to seek assistance with their caregiver role and their lack of practice in providing their wives with care, particularly assistance with Activities of Daily Living, leave them vulnerable to feelings of role captivity, depression, and stress. By quantifying the level of stress burden elderly men feel and by examining their awareness of and use of social supports, this study provides insight into avenues for education and support delivered by social service agencies.

The township in which this research project was conducted is unique due to the density of older adults: there is a paid emergency first aid squad, a nursing staff in many of the adult communities, administrative staff that are responsible for maintenance of the adult communities, a police staff that respond to the majority of health emergencies, and a host of social service personnel who work with the population that resides within the adult communities. In many other towns these services are not as expansive or do not exist. The unique character of this township makes it an ideal location to develop a Professional Training Curriculum around the issues that emerge from data collected in this study. Such a curriculum is presented in the project portion of this paper.

Summary

The purpose of this quantitative project study was to determine the relationship between perceived stress burden and perceived support, and between perceived stress burden and use of support services by EMSCs residing in active adult communities in the northeastern United States with the goal of determining what assistance and education can be provided to improve their lives. The research results have the potential to inform health care professionals about the unique needs of male spousal caregivers. Through this study, I uncovered previously unaccounted sources of stress and needs for support particular to men who might be incorporated into support practices and services available in the local community. Enhancements to caregiver support that are inspired by this study may strengthen the caregiver/care recipient dyads, improve their health and well-being, and permit infirm elderly to remain in their homes longer by identifying the educational needs of the male caregiver spouse.

EMSCs have complained to me in my role as a nurse practitioner that neighbors always ask how the care recipient is doing but they rarely ask how the caregiver is managing the day to day tasks involved with the role. This study will give a voice to these caregivers with the intention of learning what education and supports will help them. The next section describes the method by which this proposed study will be conducted. Section 3 will discuss the results and study conclusions and Section 4 will describe the project.

Section 2: The Methodology

In this study, I examined three dimensions of the experience of being an EMSC: perceived level of stress, perceived level of social support, and actual use of existing support services. I then determined the relationship between the dimensions of perceived stress burden and perceived support, and the dimensions of perceived stress burden and use of support services. Data were collected by administering three pre structured surveys: the Zarit Burden Interview (ZBI), the Multidimensional Scale of Perceived Support (MSPSS), and a Support Services in Your Area (SSYA) checklist with additional background questions.

In this section, I describe the design of this research study, the setting and sample, survey instruments used to gather data and data collection procedures, the data analysis conducted, and provisions made to ensure protection of participants' rights. In addition, I present the findings that result from this study.

Research Design

A quantitative design was selected for this study because I wished to establish statistically-verified relationships between perceived stress burden and perceived social support and between perceived stress burden and use of support services. A survey method was deemed more effective in gathering information to demonstrate these relationships, because the intention is to discover not the efficacy of a particular support method, as might be done in an experimental design, but to understand participants' perceptions of their caregiving experience as it exists generally. Creswell (2008) described survey research as providing a numeric portrayal of trends or attitudes of a population by examining a sample of that population.

Qualitative methods were considered and rejected for this study, despite the fact that most prior studies of elderly caregivers are qualitative. Many of the studies reported in the literature rely on in-person interviews of fewer than 10 subjects. The labor-intensive quality of in-person interviews naturally limits the number of participants and therefore limits the diversity of the data. Although one purpose of my study was indeed to elicit views and opinions, the starting point is pre structured by definitions of stress burden and perceived social support. A second purpose, to determine the relationship between stress and supports, was suited to correlational statistics, requiring quantitative data. Also, greater diversity of data was desired, which precluded the small sample size demanded by in-person interviews. Similarly, a case study design, in which data from caregivers, care recipients, and case workers might all contribute to a comprehensive picture of elderly care, was rejected because the purpose of this study is to determine the perceptions only of caregivers themselves.

According to Jansen (2011), the same survey instruments may be used in either qualitative or quantitative research design; it is the method of analysis that distinguishes the instruments as qualitative or quantitative. Jansen admitted “any” method of data collection in both qualitative and quantitative designs (para 15). Because it was my intention to apply statistical analysis to the data to determine relationships between the perceived stress burden and perceived social support and between perceived stress burden and use of support services, a quantitative survey design was chosen over a qualitative design, as suggested by Jansen.

Instrumentation and Materials

Participants signed a consent form (Appendix B), completed basic background information, and filled out three paper-and-pencil surveys designed to describe their perceived stress burden, their perceived level of social support, and their knowledge of available community social services. The background information sheet (Appendix F) sought to determine whether the male caregiver spouse qualified for participation in the study by determining whether the male spousal caregiver’s age was 60 years or older and resided with the care recipient. All respondents met the age and cohabitation criterion. One male caregiver spouse returned the completed survey packet after his wife had died because he believed it was important to share his information for the study. His survey was removed from the study.

Potential participants received a packet containing the surveys, the background information sheet and the consent form via United States postal mail, along with a stamped, pre addressed envelope for the return of the surveys. In an effort to widen the recruitment effort, I attached a copy of the recruitment flier to the front of the survey packet so that potential participants could review the study requirements. No caregiver who received a packet with the recruitment flier attached contacted me.

The plan was that only I would communicate with prospective participants, but I recognized that I needed additional assistance from social service agencies and physician practices when I received no response from the ad I placed in seven community newspapers. To increase participant recruitment, I gave staff at physician offices where fliers were posted survey packets to distribute to potential participants.

I processed and read all the returned surveys. Submission of a completed survey was considered implied consent.

Instruments

Participants completed a background information sheet (Appendix F), intended to confirm the participant's role as a caregiver to his wife in their home and the participant's age. This short survey of questions that were expected to be easy to answer also provided an introductory activity to help participants engage with the survey process.

Participants next completed the ZBI, which was developed by Zarit and Zarit in 1980. It is a 22-item Likert scale survey which evaluates the stress burden linked with delivering home care for a person with functional or behavioral impairments. The original survey was adapted for this study by replacing references to "your relative" to "your wife." Participants responded to questions regarding physical and emotional strain on a 5-point scale ranging from 0 (*never*) to 4 (*nearly always*). Possible scores range from 0 to 88, with higher scores indicating greater levels of caregiver burden. This survey appears in Appendix D. The ZBI gave a snapshot of each subject's level of stress burden in their role as a male caregiver spouse.

The second survey questionnaire is the MSPSS, a 12-item inventory that assesses overall perceived social support from family, friends and an unnamed special person

(Zimet, Dahlem, Zimet, & Farley, 1988). The items were rated by participants on a 7-point Likert type scale ranging from “very strongly disagree” (1) to “very strongly agree” (7). The instrument was retrieved from PsycTESTS®, a database for instruments that includes permission for non-commercial research and educational purposes. The Multi-dimensional Scale of Perceived Social Support was used to show what social supports the male caregiver spouse currently perceives in his life. Total sum of all 12 items provides a possible total score range from 7 to 84. This instrument appears in Appendix E.

The third survey used was a checklist titled Support Services in Your Area (Appendix F). This list was devised based on actual support services available in the target community as listed in local directories. Participants were asked to indicate which services they currently use from a list of services available to caregivers and older adults in the target township. They were asked to check off services which they would consider using but were not using currently. This SSYA checklist assisted with identifying gaps in services and in service use, which gaps may contribute to perceived caregiver stress.

The instruments were completed in each participant’s home in the time frame and order that best suited him. Packets containing the materials were organized thusly: welcome message (see Appendix G), consent form, background information sheet, ZBI, MSPSS, SSYA, and a self-addressed stamped return envelope. It was not necessary that the surveys be completed in any particular order. The Family Caregiver Alliance (2013) recommended that seven categories of information be solicited from a caregiver to assess a caregiver; this study addressed four of those categories: background information, stress burden of the caregiver, perceived social support, and community support services.

Instrument Reliability and Validity

Reliability and validity of the ZBI is documented. Seng et al. (2010) reported "The Cronbach's alpha value for the ZBI items was 0.93; the intra-class correlation coefficient for the test-retest reliability of the Zarit burden score was 0.89 (*n* = 149)" (p. 1). Hebert, Bravo, and Preville (2000) noted that this instrument is reliable even with variations in age, gender, living arrangement, marital status or employment status of the caregiver. Herbert et al. administered the ZBI to a sample of 312 informal caregivers in the community. The mean score was 22.4 of 88 (standard deviation: 16.2) and the median score was 18.5. There was no significant difference in the burden score according to the age, gender, living arrangement, marital status or employment status of the caregiver. The ZBI score was more strongly correlated to the depressive mood of the caregivers (*r* = 0.59) and the behavior problems of the care-recipients (*r* = 0.64) than their cognitive (*r* = 0.32) and functional (*r* = 0.31) status. Bachner and O'Rourke (2007) reviewed 138 ZBI studies and found the 22 item interview to be more reliable then shorter versions of the interview.

The MSPSS was reviewed by Dahlem, Zimet and Walker (1991) for reliability and validity. Internal reliability was measured using Cronbach's coefficient alpha with a total score of .91. This study revealed consistent internal and reliable data using a variety of subject samples including pregnant women, college undergraduates, medical school residents, and adolescents living abroad. Sajatovic and Ramirez (2012) confirmed the alpha coefficient of .91.

Setting and Sample

In this study I examined the perceptions of EMSCs who live in the same household with their ailing wife in an active adult community. Age restrictive active adult communities require one household member is 55 years of age but any other household members must be 48 years and older. To ensure that participant caregivers were themselves elderly, I set the criterion for participation at age 60 years, an age used to as a retirement benchmark (ADP Research Institute, 2013). Fulfillment of this criterion was determined by response to the question about the participant’s age on the Background Information Sheet. Although the impairment of the care recipient wife was asked on the background information sheet, unlike other similar studies, I did not limit participants to couples experiencing any particular disease or disabling condition.

The setting for this study was a single ZIP code in a rural area in the northeastern United States where many age-restricted active adult communities are located. These communities, like others advertised nationally (Del Webb, 2013b) attract couples and individuals older than 55 years with a variety of amenities and social activities. Study participants completed the study surveys in their own homes and returned them to me by U.S. mail.

The study participants were recruited from a newspaper advertisement placed in seven active adult community newspapers and through fliers placed in local physicians’ offices and other locations, including offices of local service organizations and the township office on aging. These promotional materials (Appendix H) included my telephone number and email address. Prospective participants nominated themselves by contacting me via phone or email. I chose to offer both telephone and email contact information to better match the way in which each prospective participant was most comfortable in responding. In spite of including my email address on all study recruitment literature, I did not receive any email inquiries from potential study participants.

Because the exact number of EMSCs in the target area was unknown, each active adult community phone book was tallied to discover the number of male/female couples residing within each community. Based on the resulting total number of 4560 couples, 2280 men may have been currently acting as a male caregiver spouse. According to the National Alliance for Caregiving (2009), “there are at least 43.5 million caregivers age 18 and over, equivalent to 19 percent of all adults, who provide unpaid care to an adult family member or friend who is 50 years or older” (p. 10). Based on this estimate of 19%, I expected that at least 433 elderly men (2280 x .19) in this community may be caring for a disabled spouse. According to the method described by Curran-Everett (2009), 79 participants are sufficient to yield a confidence level of 95%. Curran-Everett described a confidence interval as a range that can be expected, “with some level of confidence, to include the true value of a population parameter such as the mean” (p. 87). Therefore, the goal was to recruit sufficient participants to result in usable responses from at least 79 male caregiver spouses to participate in this study and 82 male caregiver spouses responded with usable packets.

I spoke on the telephone with twenty prospective participants who responded to the flier that was posted in physician offices and informed them of the general purpose of the study. During this conversation, I prequalified participants by asking each if he was at least 60 years of age and if he lived at home with his care-recipient wife, two criteria for participation. Participants who agreed by phone to participate in the study were mailed study materials when they shared their home address with the researcher. One participant requested that I personally deliver the study packet to his home and I was able to meet the caregiver and his care-recipient wife. There were no identifying information on returned surveys so all responses were anonymous.

Data Collection and Analysis

The results of the three measures provided me with information about participants' perceived stress burden, their perceived level of support, and a snapshot of the community services they were currently using, as well as background information that ensured that the male caregiver spouse resided with his wife and was at least 60 years of age. These four elements are depicted in Table 1.

Table 1

Variables Measured in This Study

Variable	Instrument	Measures applied
Participant eligibility	Background information sheet	Meets criteria for study participation
Perceived stress burden	Zarit Burden Interview	Mean and standard deviation per item based on 5-point Likert scale
Perceived social support	Multidimensional Scale of Perceived Social Support	Mean and standard deviation per item based on 7-point Likert scale
Use of available community-based support	Support Services in Your Area	Frequency of choice per item; total number of supports used
Stress x social support	Zarit Burden Interview and Multi-dimensional Scale of Perceived Social Support	Pearson's product-moment correlation
Stress x use of community-based support	Zarit Burden Interview and Support Services in Your Area	Pearson's product-moment correlation

As I received the completed surveys via the US postal mail, each survey was numbered in the order it was returned, from 1 to 82 and any other identifiers removed or blacked-out. My proposal had stated that I would post additional advertisements to encourage more participation but that was not done due to a zero response rate to the first advertisement in seven community newspapers.

Eighty two male caregiver spouses responded to the survey packets and all resided with in an active adult community in the township that is the focus of this study.

Their ages ranged from 61 to 92 years. The mean age of the participants was 74.8 years. All of the participants were married to a female and the number of years married ranged from 20 to 69 years. The mean number of years married was 51.96. These data are presented in Table 2.

Table 2

Participants' Age and Years Married

Variable description	*M*
Age range	74.80
Range: 61–92 years	
Years married	
Range: 20–69 years	51.96

Note. *N* = 82.

Research Question 1

Research Question 1 asked "What level of stress burden do EMSCs perceive in their caregiving role?" The male caregiver spouses responded to the 22-item ZBI; the responses had a range of 15 to 64, as depicted in Table 3. Scores ranged from 0 to 88, with higher scores indicating greater levels of perceived caregiver burden. The mean score of the individual questions for the male caregiver spouses in this study is 1.64.

Table 3

Zarit Burden Index Frequencies

Scale	0 Never	1 Rarely	2 Sometimes	3 Quite Frequently	4 Nearly always	*M*	*SD*
Question 1	18	21	31	13	4	1.68	1.09
Question 2	3	33	25	13	8	1.88	1.05
Question 3	7	18	31	23	3	1.96	0.96
Question 4	40	22	15	5	0	0.82	0.94
Question 5	21	30	20	11	0	1.26	0.99
Question 6	35	26	19	1	1	0.87	0.90
Question 7	6	15	21	24	16	2.35	1.20
Question 8	0	5	19	25	33	3.05	0.94
Question 9	16	19	32	9	6	1.63	1.14
Question 10	26	17	24	6	9	1.45	1.31
Question 11	38	27	12	4	1	0.82	0.94
Question 12	18	24	19	16	5	1.59	1.22
Question 13	40	21	17	2	2	0.84	0.86
Question 14	10	18	25	18	11	2.02	1.27
Question 15	28	23	18	8	5	1.26	1.21
Question 16	25	17	27	13	0	1.34	1.08
Question 17	26	19	23	14	0	1.30	1.10
Question 18	39	12	23	7	1	1.01	1.02
Question 19	24	19	12	19	8	1.61	1.38
Question 20	19	15	28	17	3	1.63	1.16
Question 21	19	23	25	13	2	1.46	1.09
Question 22	12	26	26	14	4	1.66	1.08

Note. N = 82.

The stress burden responses in questions 7, 8, and 14 were higher than for the other questions. Potential explanations for this follow.

Question 7: Are you afraid what the future holds for your wife?

The mean response to this question was 2.35/4.0. During the twenty years that I have facilitated a spousal caregiver support group, spousal caregivers frequently discuss what will happen to their spouse if their wife’s care needs may become so great that the male caregiver spouse will need to place his wife in a long term care facility. The responses to Question 7 confirm this fear. There is a social stigma within active adult communities about placing a spouse in a long term care facility or a day care center. As I described in Section 1, adults who purchase homes in active adult communities are seeking physical health and social interaction and placing a spouse in a care center does not support those goals.

Fifty percent of caregivers in this study used homecare services. The SSYA list did not break down the number of hours or type of home care service that participants were using. Li, Kyrouac, McManus, Cranston, and Hughes (2012) indicated that caregivers who experienced a higher level of burden were likely to report a higher number of unmet services needed such as from home care services. An education program directed to caregiver spouses to describe the benefits of home care, adult day care and long term care may help relieve the concern about a care-recipient’s future needs.

Question 8: Do you feel your wife is dependent upon you?

The mean response to this question was 3.05/4.0. One male caregiver spouse shared during a monthly support group meeting that his wife follows him around the house, he has no privacy, and she needs help even with utensil selection for mealtimes and assistance with personal care needs such as bathing and dressing. He has recently placed her in an adult day care center and states this is helping a lot, but the weekends are very long because there is no day care on the weekends for his wife, who has dementia.

Because this study did not limit to any particular disease, dependence can have a variety of causes. Care-recipients with arthritis and mobility problems may need help going to social functions which limits the social interaction of caregivers along with their care-recipient wives just as much as does a more pervasive condition like dementia.

For dementia, day care again may be an effective service to decrease dependence as demonstrated in the qualitative study by Dabelko-Schoeny and King (2010). Other services that span almost all disease specific needs would be home care service, housekeeping service, and meal preparation. These tasks can be obtained as formal services and may shift the care recipient's dependence on a formal paid caregiver.

Question 14: Do you feel that your wife seems to expect you to take care of her, as if you were the only one she could depend on?

The mean response to this question was 2.01/4.0. Home care assistance is a very acceptable form of care in the adult communities and is used by 42 of the dyads in this study. However, some care-recipients resist help from anyone other than their spouse. A comment made in the margin of the ZBI by one respondent was, "Can't get away. She resists outsiders, even my daughter. She gets physical if confronted so I see no way of using services." This sentiment is made frequently in the support group that I facilitate. The care recipient insists on help only from her spouse because she feels more comfortable with him than with a paid caregiver. Caregiver spouses in my practice report that they often leave the home while the home health aide is present so the care recipient will not demand their attention but will accept help from the health aide. It seems that day care services would give more relief to the burdened caregiver and offer socialization to the care-recipient if care-recipients could feel more comfortable using these services.

Zarit Burden Results

The global mean ZBI score is 36.58, as depicted in Table 4. This figure is similar to the mean of 35 obtained in a study of 85 Canadian spousal caregivers conducted by Sussman and Regehr (2009). These results indicate that a stress burden is felt but does not approach the highest possible levels. Ameliorating support effects may be at work among caregivers in my study or it could be that these men are able to manage their caregiving role without high levels of stress.

Pinquart and Sorenson (2005) published a meta-analysis of 58 studies that used the ZBI and reported a mean burden level of 29.9 which is lower than the results of this study. A reason for the higher level of burden in this study could be that community supports are less effective in reducing the stress burden than in previous studies. Since most previous studies have focused on female caregivers, it could be that EMSCs feel the stress of caregiving more keenly, are less prepared for their caregiving role that are women, or find social and community support less helpful than do female caregivers.

Table 4

Survey Response Data

Variable description	*M*
Zarit Burden Range Study range: 15–64	Global: 36.58 Question: 1.66
MSPSS range: 25–75	Global: 45.47 Question: 4.65

Note. *N* = 82.

Research Question 2

Research Question 2 asked, “What level of social support do EMSCs perceive in their caregiving role?” The 12 questions on the MSPSS delivered an overall score of perceived social support and also scores one three subscales: support from a significant other (questions 1, 2, 5, and 10), support from family members (questions 3, 4, 8 and 11), and support from friends (questions 6, 7, 9 and 12).

The MSPSS yielded a total score per participant of between 69 and 84 from a possible range of 7 to 84, with higher scores indicating greater perceived social support. The mean score per item on the MSPSS ranged from 4.18 to 5.04, with an overall item mean of 4.65 and a global mean of 45.47. This indicates that study participants perceive a moderate level of social support. Standard deviations are large, indicating wide differences in perceived social support. These findings are presented in Table 5.

Table 5

Multidimensional Scale of Perceived Social Support

Scale	1	2	3	4	5	6	7		
Question	Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree	*M*	SD
1	5	12	12	15	12	15	11	4.29	2.14
2	5	9	6	6	21	19	16	4.83	2.14
3	2	8	8	10	13	21	20	5.04	1.99
4	2	9	12	6	15	21	17	4.88	2.02
5	8	18	7	8	7	27	7	4.18	2.42
6	7	5	7	17	23	13	10	4.5	1.98
7	6	6	5	22	15	23	5	4.5	1.91
8	7	2	5	7	29	18	14	4.94	1.94
9	5	7	6	26	18	17	3	4.32	1.79
10	4	3	2	22	13	23	15	5.02	1.79
11	3	7	7	12	18	17	18	4.93	1.97
12	8	5	5	20	26	7	11	4.41	2.00

Note. N = 82.

To understand better participants' responses on the MSPSS, questions pertaining to perceived support from significant others, family members, and friends can be examined separately. These subscale scores demonstrate that support from family members may be most consistently present in participants' lives.

Perceived Social Support from Significant Others

Four questions on the MSPSS referenced "a significant other":

> *There is a special person who is around when I am in need* (Question 1).
>
> *There is a special person with whom I can share joys and sorrows* (Question 2).
>
> *I have a special person who is a real source of comfort to me* (Question 5).
>
> *There is a special person in my life that cares about my feelings* (Question 10).

The “significant other” mean subscale is 4.53 which is translated as halfway between mildly agree and strongly agree. Of these, Question 10 yielded the strongest agreement with a comparatively low standard deviation and Question 5 yielded the least agreement and the highest standard deviation of all twelve questions. One can speculate that the significant other imagined in response to Question 10 is the care-recipient herself, but that the capacity of the care-recipient (or other significant person imagined in response to Question 10) is limited, at least for some of the caregivers. The imagined person who cares so much for the caregiver’s feelings is yet unable to provide him with the comfort he craves. The data suggest poignancy that is, perhaps, the lived experience of care.

Perceived Social Support from Family Members

The following questions are included in the family support subscale:

> *My family really tries to help me* (Question 3).
>
> *I get the emotional help and support I need from my family* (Question 4).
>
> *I can talk about my problems with my family* (Question 8).
>
> *My family is willing to help me make decisions* (Question 11).

In this study the family mean subscale is nearly 5, at 4.91, which can be interpreted as agreeing mildly. These four questions delivered means very similar to each other and comparatively low standard deviations. Question 4 showed the lowest mean and greatest variation of these four questions, speaking to differences in the emotional support received from family members. In general, it appears, participants feel their families are mildly supportive of their caregiving role.

Perceived Social Support from Friends

The following questions are included in the subscale that indicates support from friends:

> *My friends really try to help me* (Question 6).
>
> *I can count on my friends when things go wrong* (Question 7).
>
> *I have friends with whom I can share my joys and sorrows* (Question 9).
>
> *I can talk about my problems with my friends* (Question 12).

In this study the friends subscale is 4.19, closer to 4, which indicates neither agreement nor disagreement. Support from friends is less strongly felt than support from family or from a significant other. Once again, emotional support is the most lacking (Question 9). Very few caregivers indicated very strong agreement in support of Questions 7 and 9.

Altogether, these results indicate that the male caregiver spouses in this study perceive family as their strongest support, though very few caregivers strongly agreed they have the support they need from any of their social circle, including from family. The need of these participants for emotional support is often unmet, a lack that pervades all three social subscales. These men appear to feel deeply alone even in the midst of a caring community.

Research Question 3

Research Question 3 asks, “What use of community social services do EMSCs report with regards to their caregiving role?” Caregivers responded to the SSYA list, a compilation of possible helpful services available to them. They indicated their use of each service and also whether they had considered a service but then decided not to use it.

The service most frequently used was a cleaning service and that service was used in 58 of the 82 caregiver/care-recipient homes. Home care services were used in 42 of the homes and physical therapy at an office location was used by 21 caregiver/care-recipient dyads. Services of the community nurse were used by 24 dyads, adult day care was utilized by 20 care-recipients, a caregiver support group was used by 18 male caregiver spouses, physical therapy in the home was used by 15 dyads and the Township Office on Aging was used by 12 of the caregivers. The physical therapy response could indicate the service was received by either the care-recipient or the male caregiver spouse. These findings are presented in Table 6.

Participants were asked to comment why they did not use some local support services to ease their burden. Responses ranged from, “I do not need these services yet,” to financial concerns. One participant stated that his wife will not allow strangers into the home. The most interesting verbal comment I received was from a male caregiver spouse that I spoke with in August. His wife had been in the hospital three times that year, used oxygen all the time, needed assistance with grocery shopping and depended on a walker to ambulate. He contacted me because he was not sure if he should complete a survey packet because, since his wife could still perform personal care, he did not identify himself as a caregiver!

Cleaning services were the most used and it may be that this is a service that adult children might contract for their parents, as a way of demonstrating support. It is a service that can be engaged from a distance and requires no medical qualification. A cleaning service is a convenience to any caregiver but it is unlikely that more than half of these couples used cleaning services regularly in their younger days, so the high number of participants who indicate they have used a cleaning service is suggestive.

Because the service home care was presented without definition, it is impossible to determine what participants understood that to mean; they could have understood this to indicate full time live in help or an aide who comes a few times a week to assist with bathing. This is a costly service that even on an occasional basis and its high use among these couples may again indicate assistance from distant adult children.

The community nurse is a safe resource that is readily available within the community club house and does not require a phone call to an agency to ask for assistance. The cost of community nurse visits may be bundled into the community fee, along with lawn care and club house access, so these appear to come at no charge. It is then surprising that use of this resource is not higher than it is, at less than 25 percent of respondents. The male caregiver spouse may use the nursing service for blood pressure monitoring or a resource for other questions about care, so the relatively low use of this resource may indicate a need for more outreach by the community nurse.

Similarly, services provided by the Township Office on Aging are tax-payer supported but were minimally used by these participants. Given the need for emotional support that emerged in the MSPSS, it is curious that participation in a Caregiver Support Group is indicated by only 18 of the 82 men. Both Township services and support groups may subtly favor female caregivers and may unintentionally exclude or marginalize men.

Other services, like physical therapy, adult day care, and doctor house calls may be thought too expensive or may require referrals to qualify. In this study, only 25 percent of the male caregiver spouses used day care services for their wives. Sussman and Regeher (2009) studied 85 spousal caregivers and found that the caregiver spouse experienced less stress burden when the care-recipient attended a day care program. Dabelko-Schoeny and King (2010) interviewed 28 care-recipients at day care centers and identified increase in psychosocial well-being and a decrease in dependence and perceived burden on the caregiver. Yet day care is costly; many couples may be unable to afford day care.

Some services, like counseling and Meals-on-Wheels, may carry a stigma of neediness that these men may wish to avoid. Transportation assistance may seem unneeded, since these full time caregivers may believe they and their spouses have nowhere interesting to go.

Table 6

Frequency of Used vs. Considered Support Services

Service	Used	Considered	Total
Cleaning Service	58	15	73
Home Care	42	20	62
Community Nurse	24	21	45
Physical Therapy at an office location	21	15	36
Adult Day Care	20	15	35
Physical Therapy in the home	15	9	24
Caregiver Support Group	18	3	21
Township Office on Aging Services	12	9	21
Counseling	6	15	21
Transportation Services	9	9	18
Physician who makes home visits	6	12	18
Meal delivery service	3	15	18
Online Food orders with home delivery	0	11	11

Note. $N = 82$.

The male caregiver spouses gave a variety of reasons for not seeking services to assist them with their caregiver role. Some of the reasons they chose not to use the services were that they felt capable of handling the home chores, they had the ability to care for their wife at the present time, and that services are costly and they do not qualify for financial assistance.

Research Question 4

Research Question 4 asks, “What is the relationship between perceived stress burden and perceived social support?” The ZBI question score mean was 1.66/4.0, where 1 represents low stress burden. The MSPSS mean question score was 4.65/7.0, where 1 represents low level of social support. A Pearson’s product-moment correlation was calculated to determine the strength and direction of the relationship between perceived stress burden and perceived level of social support.

The correlation obtained is -.217 which indicates that as support increased, stress decreased. This is the expected direction for this relationship, but the relationship is very weak. However, given that the perceived level of social support never rises above “mildly agree” for any question or subscale, there appears to be too little social support to impact men’s stress burden significantly. The null hypothesis is accepted, since the relationship is not significant.

The weakest area of social support was in the friends subscale and it is in this area that community-based supports could have an impact. There is little community-agency professionals can do to increase support from family or from a significant other (especially if that person is the care-recipient herself), but there is much that could be done to build stronger support among these caregivers themselves or create a stronger friend-like relationship between caregivers and community professionals. The low correlation between stress burden and social support is less a fact than an opportunity. There is much that could be done to enhance the action of social supports in reducing men’s stress burden.

Research Question 5

Research Question 5 asks, “What is the relationship between perceived stress burden and use of community social services?” To answer this question, a correlation between the results of the ZBI and the number of community social services that participants reported using was calculated. The result was not significant with a Pearson product moment correlation *r* = .046. The null hypothesis was confirmed by this finding.

A closer look at the results of this study may reveal a reason why community-based services have no impact on these participants' stress burden. First, these men admitted to a fairly low stress burden, so that the impact of community based social services might be negligible. It also appears true that support from friends, family, and a significant other has little impact. Certainly, it is possible that these men take caregiving in stride and have no need for community based support or even support from friends and family. But another finding from this study refutes that: these participants consistently cited a lack of emotional support and comfort. The community based services used most frequently are the services that are the least personal, housecleaning and in home care of the care recipient, and among those used least are ones that could address the need for emotional support: a support group and counseling. It might also be that the community based services that can address the unmet emotional needs of these men are lacking or are available but simply not a good fit for them. This result may indicate that current community services are not relevant to men, and that these services could be improved to meet the needs of EMSCs.

Table 7 presents a summary of participants' responses to the ZBI, the MSPSS, and the number of community-based services used. In general, the greater the levels of perceived stress, the more community-based services were used.

Table 7

Perceived Stress Burden, Social Support and Use of Services by Participant

PARTICIPANT	Perceived social SUPPORT	Perceived STRESS	Used SERVICES	PARTICIPANT	Perceived social SUPPORT	Perceived STRESS	Used SERVICES	PARTICIPANT	Perceived social SUPPORT	Perceived STRESS	Used SERVICES
1	5.25	1.5	4	29	4.75	0.86	5	57	2.41	0.72	3
2	4	1.4	5	30	4.83	0.36	1	58	5.3	2.59	4
3	4.5	1.5	1	31	6	1.18	1	59	4.75	2.72	2
4	5.8	1.68	3	32	3.5	1.86	3	60	5.33	0.63	3
5	3.75	1.31	3	33	3.16	2.63	0	61	5.91	0.59	3
6	5.35	1.18	0	34	5.33	0.54	3	62	4.08	1.59	3
7	2.41	2.8	4	35	4.9	0.5	2	63	3.16	1.81	3
8	5.3	0.9	3	36	2.5	2.09	1	64	6.08	1.81	4
9	5.41	0.68	3	37	3.91	2.27	3	65	2.41	1	3
10	4	0.63	3	38	6.16	0.4	1	66	3.83	1	3
11	5.41	0.59	3	39	5.41	1.18	2	67	3.53	2.22	3
12	4.33	1.59	3	40	4	1.68	4	68	4.83	2.31	2
13	3.75	2.72	6	41	5.25	1.5	4	69	3.75	2.59	4
14	3.91	1.27	1	42	4	1.4	4	70	5.91	2.22	2
15	4.83	1.09	0	43	4.5	1.5	5	71	2.75	2.04	3
16	5.91	1	3	44	5.8	1.27	3	72	3.5	2.04	3
17	6	1.86	5	45	3.75	1.31	3	73	3.91	2.22	4
18	2.08	2.59	1	46	5.91	1.18	3	74	2.75	1.95	2
19	5.5	1.86	3	47	6	2.86	2	75	6.25	1.86	2
20	3.83	2.36	2	48	2.08	0.9	3	76	6.25	2.31	3
21	5.25	1.18	0	49	5.5	0.68	3	77	5.91	2	3
22	2.41	2.31	2	50	6.25	0.72	3	78	6.16	2.27	2
23	4	2.22	3	51	5.41	0.45	3	79	6	2.9	3
24	5.75	1.09	5	52	6.25	0.72	3	80	4.83	1.68	3
25	5.66	1.04	4	53	3.75	0.72	4	81	5.25	2	2
26	3.16	1.81	4	54	3.91	2.63	4	82	3.58	0.45	3
27	3.58	1.9	3	55	4.83	1.09	4				
28	4.83	1.4	3	56	3.16	1	2	**Totals**	**375.18**	**126.46**	**234**
								Means	**4.58**	**1.54**	**2. 85**

Assumptions, Limitations, Scope, and Delimitations

The purpose of this quantitative project study was to determine the relationship between perceived stress burden and perceived level of social support, and between perceived stress burden and use of support services by elderly male caregiver spouses residing in active adult communities in the northeastern United States, so that education can be provided to improve their lives. I assumed that the caregiver participants answered the questions honestly. I also assumed that the responses returned were representative of all EMSCs. By choosing to live in an active adult community the participants chose a life style that offers stimulation and recreation. I assumed that participants in this study shared the community's values of active retirement.

This study was limited to one ZIP code in the northeastern United States and it included only caregiver spouses who live in an active adult community. Due to a small sample size and the limitation of living in active adult communities, the results may not be representative of the EMSCs in general. In addition, since adult communities in the target area do not permit recruitment for research within the clubhouses, I had to recruit participants through advertisements in community newspapers and through contacts at local social service agencies and physician practices. When no male caregiver responded to the community newspaper advertisement, an ad was printed and attached to envelopes containing the research packet. Physician offices and social service agencies distributed the packets to male caregiver spouses who were willing to accept them. The inability to recruit in the clubhouses may have limited my ability to recruit the widest pool of participants.

The scope of this study encompassed the relationship between perceived stress burden and perceived social support, and between perceived stress burden and use of community social services among elderly men who provided care to their ill or disabled wives. Data were gathered through surveys of 82 participants.

The study was delimited by its sample of male spousal caregivers over the age of 60 years who spoke English. All of the participants resided within an active adult community in a single ZIP code in a rural township in the northeastern United States. All of the intended participants cared for a wife who is ill or disabled.

Protection of Participants' Rights

I received IRB approval (#07-30-14-0149191) from Walden University in July 2014 prior to contacting and recruiting of participants. Following IRB approval, recruited participants received a packet of surveys and consent in one envelope. Returned surveys constituted implied consent.

None of the surveys requested the names of respondents. Completed surveys and the data will be kept under lock and key in my home for a five year period at which time all data will be destroyed. No file will be stored electronically on a hard drive but instead stored on a thumb drive and locked up for five years from the conclusion of the study, at which time it will be destroyed.

Summary

In this quantitative project study, I used three surveys to explore EMSCs' perceived relationship between perceived stress burden and perceived social support and between perceived stress burden and use of social services; based on responses that established their perceived stress burden, perceived level of social support, and their awareness and use of community-based social services. The results of this study of 82 male caregiver spouses indicated that even as stress increases, perceived social support remains about the same ($r = .21$), and that use of community based social services has no impact on perceived stress.

Men in this study's group of EMSCs report moderate support from family and friends and they avail themselves of community support services, particularly housecleaning services and in home care. Use of community supports was not related to perceived stress, though, in general, the more burden caregivers felt the more they relied on community and social supports.

Numerous community and social services are available in the township where the active adult communities that were the focus of this study are located. The male caregiver spouses in this study did not identify unmet needs for support services or suggest how additional services might diminish their caregiver burden. Nonetheless, it is clear that community support is vital to caregiver well-being. It is hoped that the study results when shared with agencies that provide services to caregiver/care-recipient dyads will lead to stronger support for elderly couples, greater identification of educational interventions that can assist EMSCs and improvement in the outlook for this growing segment of the United States population.

A workshop was developed for the geographical location of the study. The purpose of this workshop is to share with agency professionals the challenges facing male spousal caregivers, particularly the relationship between perceived stress burden and perceived social support and the relationships between perceived stress burden and use of support services. Section 3 will feature the project and Section 4 will include the outcomes and recommendations for future study.

Section 3: The Project

Section 3 includes the project based on the EMSC study results, determined using the (a) Zarit Burden Index; (b) the Multidimensional Scale of Perceived Social Support; and (c) a checklist, Support Services in Your Area. In the EMSC study, I used quantitative surveys to determine the perceived stress burden, level of social support, and use of community social services as experienced by EMSCs living in active adult communities in a rural township in the northeastern United States. Results of this study indicate that EMSCs experience low emotional support but that they do not use support services that could provide emotional support. In the project, I will describe this gap to support service professionals and guide them in filling this need for EMSCs.

This section introduces the proposed project and the project goals. A literature review is presented to support the project. Subsequently, implementation strategies will be discussed, along with implications for social change and a proposed project evaluation.

Brief Description of the Project

The goal of the project is to inform agency personnel who work with caregiver/care recipient dyads of the needs of EMSCs, with the intention of improving services for this underserved population and thereby increase outcomes for these caregivers and for their care-recipient wives. This goal will be accomplished through a 3-day training workshop designed to make professional personnel more aware of the stressors and support needs of the male caregiver spouse. As part of the proposed training workshop, these agency personnel will design a curriculum for their organizations around services to meet the education needs of EMSCs for increased skill and confidence in their caregiving role. This training workshop will begin with an agency needs assessment performed by workshop participants to establish a baseline of current interactions and supports with male caregiver spouses and the outcomes of those interactions. The training workshop will also evaluate the need for change. This needs assessment will be used to develop pertinent and meaningful content for the learners and will be delivered to me 5 weeks prior to the training workshop to ensure the relevance and applicability of workshop topics.

Rationale

Three-day training is an appropriate manner in which to share the information with professionals from a variety of agencies. This project will invite professionals from several agencies that work with caregiver spouses to participate in a 3-day training program. For most agencies, it will be easier to dedicate 3 consecutive days to training as opposed to shorter length classes during a period of several weeks.

Boulton (2014), in a study of teacher workshops related to bullying among pupils, found that a 3-day training session was more effective than shorter training sessions. Similarly, a 3-day educational program about root cause analysis (Wakefield, 2012) gathered 18 professionals from multiple departments for the training program and accompanying qualitative study. Wakefield (2012) found that the majority of participants believed that the 3-day program achieved its goals.

Review of Literature

To facilitate the literature review, education, nursing and multidisciplinary databases were accessed. Within the education databases, Education Research Complete, ProQuest, ERIC was searched. The nursing databases Ovid Nursing, Cinahl Plus, and Proquest Nursing and Allied Health Source were explored. Finally, the multidisciplinary databases Thoreau and ProQuest Central were examined.

Search terms were entered into these various databases. Search terms included *adult learners, adult learning*, *conducting a professional training session*, *curriculum, evaluation*, *learner centered learning*, *learning methodologies*, *teaching methodologies*, *training sessions for professionals*, *workshops*, and *workshop efficacy*. Boolean phrases related to workshops included *education and program planning*, *human resources and workshop training*, *multiple professional training sessions*, *nursing and workshops*, *workshop efficacy*, *workshops and efficacy*, and *workshop planning*.

The objective of this 3-day workshop is to assemble a variety of professionals in the township area where the study took place and share knowledge regarding male caregiver spouses. Caffarella (2010) identified six key factors of learning transfer that include program participant, program design and execution, program content, changes required to apply learning, organizational content, and community and societal factors (p. 222). Merriam, Caffarella, and Baumgartner (2007) characterized adult learning as the integration of circumstances and learner perspective and it is this integration that this workshop hopes to achieve.

Organizing Framework

The adult educational theory of Knowles (1989) was used to plan the proposed program. Organizing frameworks guide curriculum development and provide venues for evaluation of the course for comprehensiveness and quality (Keating, 2006).

Andragogy, brought into the mainstream by Malcolm Knowles (1989), often is referred to as a learner-focused method of teaching. Knowles detailed key assumptions about adult learners; these assumptions became the foundation of adult learning theory. Children learn in school, which is a continuous learning environment; adults in the workplace learn discontinuously, according to need (O'Toole & Essex, 2012). Knowles emphasized that adults will have had multiple life experiences and have more established beliefs then children. In addition, adults focus more on the procedure and significance of learning, rather than the content of curriculum.

Andragogy is based on a set of six assumptions that are essential to adult learner curriculum design (Knowles, Holton & Swanson, 2012). The first four assumptions include the self-concept of autonomy and self-direction, the role of the learner's life experience, readiness of an adult to learn, and the adult's orientation to learning. The last two assumptions were later added to Knowles's model and encompass the internal motivators of adult learners and the fact that adults need to know the reason for new learning before they undertake a task (Knowles et al., 2012).

Knowles's original set of six assumptions were further revised and refined to become the core adult learning principles of the andragogy in practice model (Knowles, Holton & Swanson, 2012). This conceptual framework applies andragogy across multiple spheres of adult learning to include: goals and purposes for learning; individual and situational differences of learners; and core adult learning principles of andragogy. The proposed 3-day workshop will have goals and purposes; and take into consideration the individual and organizational differences of all the workshop participants.

Program Participants

Participants invited to participate in the development and execution of the program will include social workers, client managers and program personnel from local nursing homes, home care agencies, Jewish Family Service, active adult community administration offices, first responders, public libraries, and township social service agencies. Pavelin, Pundir, and Cham (2014) recommended that creativity is stimulated when workshop attendees are solicited from different groups because this will expose participants to different perspectives and will enrich the learning experience. According to Pavelin et al. it is helpful to aim for diversity in participant experience, opinions and level of seniority in planning an interactive workshop. I anticipate that between 20 and 30 participants will attend.

As suggested by Westfall-Rudd (2011), participants should have involvement into the workshop planning process and selection of presenters for a program in order to develop a feeling of ownership for the workshop. One way to do that is to invite participating agencies to nominate a colleague who is knowledgeable in caregiver spouse relationships to speak at the event or have input into the planning process.

According to Caffarella (2010), program design can be implemented before, during and after the training program. Several studies indicated that pre-workshop surveys are an opportunity for participants to contribute ideas and determine their level of experience related to the workshop topic (Forhan & Law, 2009; Harwell, Law, Ander, & Helgerson, 2008; Pavelin, Pundir, & Cham, 2014). Information mined from such a survey can assist with developing the design instruction.

Workshop Design

Content. Planning and designing for instruction is essential to ensure that learners achieve the intended outcome (Dean, 2004). Common elements found in curriculum for adults include: goals, content, methods and evaluation (Knowles, et al., 2012). Knowles, et al. describe that the elements are prepared for the learner in advance and the objectives are expanded in the content.

Knowles (2012) places Setting Objectives as Step 5 in his Process Elements of Andragogy and states that the approach for setting objectives should be by mutual negotiation between the teacher and the learner. Dean (2004) differentiates between goals and objectives by defining goals as broad and objectives as actions that can be derived from the goal (p. 105). According to Johnson (2009) objectives provide the benchmark on which to base the measurement of student learning. Formulating a goal is important to adult learners, because adult students desire to make progress toward accomplishing the goal (Comings, 2007).

Dean (2004) suggested that the adult educator is expected to be the content expert and to work with other content experts to create educational material for a workshop. Baptiste (2003) suggests that subject matter is not static but is influenced by the teacher's relationship with the subject and how she views the complexity of the subject matter and the relationship that the students have with the subject. Content as defined by Heimlich and Norland (1994), "Content is the specific domain of knowledge, skills, abilities and processes, and affect addressed during the teaching and learning exchange. It is often referred to as curriculum, subject matter, or program, indicating a very specific focus" (p. 51). The content of the proposed 3-day workshop will be developed from the Male Spousal Caregiver study results and information related to caregiving spouses in general.

Method. Using a method based in Adult Learning Theory is important for the transfer of learning. Axelrod et al. (2011) compared the feelings of 100 care aides concerning a self-study program and the same content delivered through an interactive training program. Study participants showed a preference for interactive training and completion rates were higher for participants in the interactive training group than for those in the self-study group. However, it is more expensive to provide interactive training course when compared to the cost of providing training through self-study (Axelrod et al., 2011). Interactive learning included active learning exercises, case studies, or storytelling, or a combination of these as the preferred method of learning by the students in studies conducted by Axelrod et al. (2011), Blewett and Kisamore (2009) and McCausland and Meyers (2013). In the project described in Appendix A, participants will engage in listening, guided discussion, work in small groups and dyads, video presentations, and simulation exercises, as well as in creating an application based on their observation of their own work sites and clients.

Active learning exercises. Active learning is described by Baeten, Kyundt, Struyven, and Dochy (2010) as a teaching approach that compels students to move away from receiving knowledge and participate with class material in a direct way. These authors found that while learners in different fields were more or less engaged by active learning exercises, those in the social sciences found these methods most helpful.

One example is a study reported by Young, Griffin, and Vest (2013), who investigated the impact of an active learning exercise at a workshop for pharmacology students, who viewed a 5-minute skit of a counseling session on emergency contraception using a mock patient and a student acting as a pharmacist. Following the skit, the students were given a checklist of counseling points and asked to pair up with a classmate and practice counseling with each other regarding the use of emergency contraception. The entire process of pretest, skit, practice counseling session, and posttest took about 40 minutes and resulted in 95% of students indicating they were more confident in their ability to counsel patients on emergency contraception after experiencing the interactive session. Blaine et al. (2008) reported similar results in an interactive training program for physicians in ways to present genetic counseling.

Case studies. According to Marsick (2004), the advantage to using a case study when teaching content is that participants actively interact in a group and have to solve problems similar to a real world situation. Case studies have been used effectively to convey a variety of topics from medicine to agricultural topics (Dow & Jacques, 2012; Freeman, & Le_Rossignol, 2010; Porcheret, Main, Croft, McKinley, Hassell, & Dziedzic, 2014; Westfall-Rudd, 2011).

Dow and Jacques (2012), in conjunction with a Canadian automobile association, developed an interactive 90 minute case study program for physicians to assist them in assessing driver capability in older adults. Their results demonstrated that replacing the lecture series with a more interactive workshop using case-based discussion led by a physician was a major factor in the program’s success. The lively discussions that occurred during the presentations increased physicians’ interest in determining driver fitness and in guiding driver cessation.

Storytelling. According to Clark (2010), storytelling is a way for workshop participants to share their personal story and liberate their feelings about a segment or event in their story. This element would be a wonderful addition to the workshop day to highlight the shared experience of support professionals across the variety of organizations and occupations that deliver support services. The richness of the caregiver’s story, as described by support professionals, will help bring to life the personal nature and profound impact of the caregiver burden.

Evaluation. Cafarella (2010) defined program evaluation as the method used to conclude if the design and delivery of a program were successful and whether the planned outcomes were met. He believed that the evaluation process is used to improve future programs and assess how the program impacts processes and outcomes. In 2007, Woodward evaluated a training program for new hires within a company to determine if the concept of andragogy translates into the workplace. After incorporating Knowles's concepts of andragogy, new hires were more informed and his theory converted into workplace learning. Augustsson, Törnquist, and Hasson (2013) found that staff had gained new knowledge and insight into the care work, and had learned more about their co-workers' ways of working at an individual level. This manner of evaluation demonstrated to the authors that evaluation is part of the learning process and is beneficial to individuals even when learners' efforts did not alter outcomes at the organization level.

These methods will be incorporated into a 3-day workshop for support professionals working with elderly caregivers in a single township in the northeastern United States. In the following sections I will describe the purpose and goals of that project.

Purpose of the Project

The purpose of this professional development/training curriculum is to assist the staff from agencies that interact with caregiver spouses, particularly men, in identifying the needs the male caregiver spouse and how to respond to him in his caregiver role. This project will provide opportunities for information from the study to be disseminated to agencies that work together with the male caregiver spouse.

Goals of the Project

The goal of this proposed 3-day professional training program is to familiarize professional participants with the needs of the male caregiver spouse. The anticipated program participants will be personnel who work for the agencies that interact with caregiver/care recipient dyads in the surrounding township.

By the end of the three days of training, participants will be able to competently work together with EMSCs so that the caregiver spouse can effectively and knowledgeably fulfill his role as caregiver. On the last day of the training, participants will develop a male caregiver spouse curriculum for their agency to assist and support the male caregiver spouse in his caregiver role. Each participant who completes the training program will be able to share information with the agency they represent. It is hoped that within three to six months of completing the workshop series, agency participants will have developed and begun to implement clearly defined guidelines and processes when interacting with a caregiver spouse.

Ideally, male caregiver spouses will participate in the Caregiver Training Curriculum, but the demands of caregiving may not allow them to participate in the full three day curriculum. Male caregiver spouses will be invited to attend one day of the curriculum that will be presented to service providers and the caregivers.

Implementing the Project

I will contact local agencies five months prior to the planned program to invite staff participation in the project. Agencies will agree to a 3-day commitment for their staff to participate. The agencies will then share names of their personnel who would profit from attending this training, so I may extend an invitation to them via email.

The room and audio visual equipment will be provided by the hospital that I work for at their township site so that participants will not have to travel a great distance. A large conference room with moveable tables and chairs will be needed. Furniture that can easily be moved will accommodate a variety of teaching activities to facilitate a variety of learning styles. The ability to control lighting and room temperature is important to the success of the workshop, as are adequate electrical outlets and available LCD projector, viewing screen, and high-speed Internet. An adequate number of restrooms; elevators, ramps and handicapped parking spaces are also necessary. All of these requirements can be met through the target hospital’s facilities.

I will apply to the Township Office on Aging for a grant to pay for refreshments during each of the three workshop days. Morning and afternoon snacks will consist of coffee, decaffeinated coffee, water, tea, fruit and the choice of a muffin or bagel in the morning. At midday, box lunches including a choice of vegetarian selections and sandwiches, fruit, and a cookie or similar dessert will be offered, along with beverage choices.

A guest presenter will be included in each of the three workshop days, in addition to being the main presenter. Rutgers University has a social worker who lectures on caregiver issues as a community service and she will be invited as one of the speakers. I will invite two other local experts with caregiver expertise to share in the role of presenter.

A detailed budget for this 3-day workshop is included in project plan (Appendix A). I anticipate that this training can be delivered at a cost to participating agencies and organizations of $105 per individual learner, or $35 per 8-hour training day. This estimate seems reasonable and in-line with similar professional development events.

Anticipated Barriers

Caffarella (2010) recommends that a program planner invite selected learners to assist in planning a new workshop. The proposed workshop will include participants from a wide range of often competing organizations. It is critical to the success of this program that learners subscribe to the idea of a male caregiver spouse education program and support the program by allocating staff and by contributing their financial and intellectual resources to the project.

Avillion (2007) found that one barrier to designing effective workshops is the lack of time for an instructor to develop, facilitate and evaluate the workshop. This may be a problem when recruiting expertise from other organizations and relying on their professional dedication to the community to fuel their participation. Since the township in which this workshop event will occur has a notable older adult population, commitment to this program may be perceived as a professional obligation rather than an elected benefit. Some participants may not see a personal professional value in contributing to the design and execution of the program, and may not voluntarily attend and engage in the learning process (Caffarella, 2010; Knowles et al., 2012). My plan is to meet with a few stakeholders privately, prior to launching the meeting preparations. Recruiting township leadership support is critical to the success of the workshop.

Project Implementation Timeline

The timeline for implementing the 3-day workshop is presented in detail in Appendix A. Preparation for the workshop series will begin 20 weeks ahead of the intended first workshop day, with an invitation to stakeholders to contribute ideas to the workshop plan. Stakeholders will also be asked to nominate prospective participants and provide me with their names and email addresses. Invitations to prospective participants will be sent via email eight weeks prior to the first workshop day.

Each of the three workshops will be separated in time by two weeks, during which participants will be asked to observe and reflect on the application of workshop ideas to their own situations and clients. This means that the three workshop days will occur over a period of one month. After each workshop, participants will be asked to evaluate the success of the day and suggest further learning topics for future dates. An evaluation of transfer of learning will be made three months and again six months following the final workshop day. An interim report of workshop effectiveness will be made to stakeholders following the three month evaluation and a final report following the six-month evaluation.

It is my hope that by extending the time of the project over so long a period that the issues of male spousal caregivers will become part of the fabric of professional service in the target township. The detailed timeline for this project is included in Appendix A.

Project Evaluation

In order to evaluate the proposed project, it is essential to share the goals and objectives with participants and stakeholders because the evaluation process flows from the program goals and objectives. Sharing the goals and objectives allows the participants to understand the information that will be transferred during the program. When adults see relevance to the activities, they are more likely to remain in the learning setting (Merriam, Caffarella & Baumgartner, 2007).

Program evaluation is discussed by Caffarella (2002), as the process to determine if the program plan and administration of a program were successful and the planned outcomes were met. Once the project is completed, anticipated next steps will be determined via participant feedback and formal evaluations. Cafarella (2002) described the evaluation component as important to understand the strengths and weaknesses of the program and to use the findings as a basis for future improvement. Since there are multiple stakeholders in the proposed program, it is essential to develop an evaluation plan that will determine if the program goals were met and if there was knowledge transfer. Stakeholders will benefit from a complete evaluation to determine if their investment of time and personnel was beneficial. After the evaluation is completed, program revisions should be based upon evaluation data and results will be distributed to all key stakeholders.

The evaluation for the 3-day workshop will be derived from the programs goals and objectives. According to Billings and Halstead (2005), the steps of a comprehensive evaluation process all require action: “1) identifying the purpose of the evaluation; 2) identifying a time frame; 3) determining when to evaluate; 4) selecting the evaluator(s); 5) choosing an evaluation design/framework or model; 6) selecting an evaluation instrument; 7) collecting data; 8) interpreting data; 9) reporting the findings; 10) using the findings; and 11) considering the costs of evaluation” (pp. 445-446). These steps are included in the evaluation of the 3-day workshop.

The two types of evaluation planned for this workshop will be formative and summative guided by the workshop goals and objectives. A formative evaluation is projected to enhance and correct programs, during the program (Keating, 2006). The time frame for the evaluations will be prior to the programs initiation, during the program, at the end of the program and three months after the program is finished. One of the project goals is that within three months of completing the workshop series, agency participants will have developed and begun to implement clearly defined guidelines and processes when interacting with a caregiver spouse. Final evaluation results will be shared no later than six months following the end of the workshop with program participants, program planners and organization stakeholders. The evaluation tools and the evaluation process will be coordinated by the program facilitator and at least one organizational stakeholder.

The formative evaluations will be used after the first and second workshop to amend the program to meet the needs of the learners. The next type of evaluation to be used will be the summative evaluation. According to Caffarella (2010), the summative evaluation occurs when the program has finished. The summative evaluation at the completion of the third workshop will be information for the planners to adjust a future edition of this program.

The evaluation goals will be used to edit the program during the workshops using the formative evaluation process and to alter any future planned programs, using the summative evaluation results. Results of the evaluation data will be shared with all program participants and all the organizational stakeholders that participated in the program planning. The overall evaluation goal is to determine if a caregiver training curriculum has been developed for support personnel in each participating organization to use when interacting with a caregiver spouse.

Implications for Social Change

In concert with Walden University's commitment to social change**,** this project study was designed to benefit the caregivers and care recipients in the target community. Male caregiver spouses have been inadequately studied in the literature and this study contributes to information related to them and their perceived support while living in active adult communities. It is my intention that home care agencies when presented with some of the burdens that the male caregiver spouse endures, they may offer more flexible services that meet the unique needs of these men.

The 3-day training described in this project is an opportunity for agencies to create relationships and break out of their silos and traditional procedures. The workshop is also an opportunity to introduce agencies and their services to the male caregiver spouse. Recognizing that the male caregiver spouse needs assistance and support to fulfill his role, working together to provide supportive services is a potential outcome.

A large amount of attention has been focused in the literature on the adult caregiving daughter, but society in the United States is aging and an increased attention is needed to the plight of elderly caregiver spouses. This study has the potential to contribute to the happiness and health of EMSCs and their care-recipient wives, permitting both of them a more satisfying, financially secure, and comfortable existence.

Section 4: Reflections and Conclusions

The final section of the project study includes a discussion of the project strengths, limitations, and recommendations derived from the research findings and proposed project. An analysis of project development, my personal scholarship, and leadership attributes are described. An overall reflection of the project study, its implications, applications, and directions for future research are summarized.

Project Strengths

In this project study, I examined the perceived stress burden, social support, and availability and usefulness of support services for EMSCs, with the intention of determining what assistance and education can be provided to improve their lives. The EMSCs in this study perceived a high level of social support.

Eighty two EMSCs responded to the survey packets and all resided within an active adult community in the township that is the focus of this study. Their ages ranged from 61 to 92 years. The mean age of the participants was 74.8 years.

The strength of the study was the ability to attract 82 EMSCs to respond to the study. There was no response to ads placed in seven community newspapers, but my access to many physician practices and social service agencies assisted with participant recruitment. This is strength because solicitation of community residents within club houses is prohibited by community bylaws.

Four separate surveys were used to explore the perceived challenges faced by EMSCs, their perceived level of social support, and their awareness and use of community social services, including supports they wish they had but cannot find. The results of this study of 82 male caregiver spouses indicated that even as stress increases, perceived social support remains about the same; that was not the expected outcome for this study. Men in this study's group of EMSCs have reasonably strong support from family and friends and they avail themselves of community support services. Use of community supports was not strongly related to perceived stress, though, in general, the more burden caregivers believed that the more they relied on community and social supports. I also found that many EMSCs did not recognize themselves as caregivers but instead viewed themselves as husbands who helped their wives, which they viewed as an extension of their marriage vows.

Project Limitations

This project study had limitations. To begin, the sample population may have been encouraged to participate by agencies, physicians, and friends. Due to my long working relationship in the communities, when community residents discovered that I was the research director, they contacted friends who were caregivers and told them about the study and encouraged the EMSCs to contact me. Although I mailed packets to more EMSCs than were returned to me, some EMSCs may have been compelled to participate in the study. The sample may not be representative of all male caregiver spouses from other communities in the United States. I used a self-reported survey and this may limit the generalization of the survey results. Survey research cannot be used to explain cause and effect; rather, survey research describes trends in data (Creswell, 2012).

Care recipients had a variety of illnesses in contrast to many studies that limit illness to a single disease for a study. Previous studies have targeted situations in which the care-recipient was diagnosed with Alzheimer's disease (Knutsen & Raholm, 2009; Sussman & Regehr, 2009; Valimaki, Vehvilainen-Julkunen, Pietila & Pirttila, 2009). I felt strongly when designing the study that all illnesses should be included but I can see now that it has contributed to a limitation of the study.

Recommendations for Alternative Approaches

An alternative approach would be to consider couples in which all care-recipients share a single diagnosis and to continue to recruit participants with fliers and newspaper ads. This would add time to participant recruitment but would eliminate physician practices and agencies from contacting male caregiver spouses and encouraging them to participate in the study. I am not sure if a researcher not connected with the active adult communities could have achieved recruitment of 82 male caregiver spouses due to how closely the active adult communities guard their privacy with regulations to prohibit research. I would recommend financial compensation or the opportunity to win a gift card to recruit EMSCs for future research.

Scholarship

Scholarship is a process of learning and expanded thinking. Thoun (2009) recognized that scholars “develop according to their own beliefs, values and scholarly interests” (p. 556). The progression from student to scholar evolves over time and allows the student to approach a project with purpose and seek academic evidence to affirm and refute research concepts. My doctoral journey has been longer than some students, but I recognize that my final decision of what and whom to study was a process that was necessary to my ability to stand where I am today. Reading countless articles and evaluating their value and contribution to my study has taught me to seek different points of view and enabled the development of my critical thinking and reflective writing.

Project Development

Project development begins with collective goal setting and evolves via cooperative curriculum exchange between program leaders and program participants. The curriculum in this project requests that participants evaluate the workshop after each workshop day to allow the curriculum be fine-tuned to the adult learners’ needs and permit the transfer of knowledge, the underlying goal of the 3-day workshop.

Program planners need to reflect on the goals and mission statements of all of the organizations participating and align the curriculum goals of the workshop program. In order for the transfer of knowledge to occur and for each organization to incorporate the knowledge into their organizations, goals and expectations from all program partners need to be acknowledged. As a result of this project study, I have learned that it is critical to engage all of the stakeholders plan the program with transparency and input from all organizations that are participating, and design the workshop programs with evaluation in mind to assess if the transfer of knowledge has occurred.

Leadership and Change

Numerous articles and books have been written about change because change is not a process that individuals typically welcome; it is easier to maintain the status quo. A change in an organization is challenging to implement and difficult to maintain (Austin, 2009). The change management leader can be seen as a tool to operationalize and implement change in organizations. Given that the 3-day workshop project involves several community organizations, the leader must be approachable and fluid depending on the agency that is being interacted with at the time. According to Boykins, Campbell, Moore, and Nayyar (2013), no one particular management style has been found to appeal to all team members studied and multiple leadership styles are needed to get results from all team members.

It is anticipated that several agencies will participate in the 3-day workshop and have similar client populations because of the older adult population demographic found in the municipality, but also I expect that they will all have different mission statements that drive their organizations. Given the diversity of the agencies that will be invited to participate in the program, transformational leadership will be a necessary skill to accomplish the execution of this project. Transformational leaders influence, while transactional leaders enforce (Whittington, Coker, Goodwin, Ickes, & Murray, 2009). Charisma has been recognized as a form of personal power (Bass, 1960; Etzioni, 1961).

Developing this 3-day workshop with several agencies will be challenging and difficult at times but I believe that the core value of all of the agencies is to provide quality services to the older adult population they serve. Transformational leadership with passion and the ability to stimulate and motivate fellow stakeholders is necessary to take the project from paper to a living workshop. This project has taught me how interdependent agencies are in the township and the importance of leadership to change the way many of the agencies care for caregiver/care-recipient dyads.

Reflection on the Importance of the Work

The research study described in this paper supports the finding that male caregiver spouses experience stress burden and that society needs to address their issues. No other study has studied individuals who reside in active adult communities. Homeowners association rules clearly define and govern activities within the clubhouse and promoting research is not supported by the governing bodies. This paper contributed to the body of information known about male caregiver spouses. It is evident that male caregiver spouses need more information about resources in an effort to manage their stress and care for their wives.

Implications, Applications, and Directions for Future Research

A major issue was that despite advertising in seven community newspapers, not one caregiver responded to the ad placed in the papers. Future researchers need to find more effective methods to reach caregiver spouses. The assistance that I received from physician practices and social service agencies was invaluable in locating male caregiver spouses.

Conclusion

Section 4 included the project strengths, limitations, recommendations, and reflections of my doctoral journey. I realized early in the study that recruiting research participants via the newspaper was an ineffective mode for my study. Reaching out for assistance to agencies and physician practices was a recruitment strategy that evolved and involved critical thinking. This study of male caregiver spouses may not be applicable in other settings. I am grateful for the support that I received from other healthcare professionals and am delighted that the study participants were residents of active adult communities, a population that is poorly represented in the literature.

Although this journey in nearing the end, I have thought throughout this process about how it could have been done a bit better, or what other information would I have liked to gather about the male caregiver spouse. So at the end of this journey I recognize that a scholar does not end the journey but continues to seek new information to contribute to a body of research. My successful completion of the doctoral program had many detours and challenges but I feel that for my journey to success, a sentence often attributed to Dale Carnegie reflects my experience nicely: “Flaming enthusiasm, backed up by horse sense and persistence, is the quality that most frequently makes for success.”

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Appendix A: The Project

Supporting the Male Caregiver Spouse:

A 3-day Workshop for Service Providers

The results of this doctoral study will be shared with service providers who work with EMSCs, with the purpose of improving supports for these caregivers, whose unique needs have been largely overlooked. The results will be shared in a workshop delivered over three days.

Purpose

The purpose of the project is to provide a training workshop to facilitate a change in service agencies in the manner in which they interact with male caregiver spouses. As evidenced by the research findings in Section 2, there did not appear to be a directional relationship between stress and support services use, or a directional relationship between stress and support by family, friends, or significant other. However, a need for more emotional support emerged from the findings, which forms the basis of this project. By providing men with a more supportive community of care, those male caregiver spouses who have not considered community-based support services may reconsider their decision.

Goals

The primary goal of the program is to change the manner in which services are offered to male caregiver spouses by educating service providers regarding the caregivers’ struggle and the emotional needs they have resulting from their care of their wives at home. The interactive workshop will provide opportunities for experiential learning for the service providers.

Objectives and Anticipated Outcomes

I designed the learning objectives prior to contacting and distributing a needs assessment from the project stakeholders. A need assessment will be disseminated to the learners and stakeholders 4 weeks prior to the workshop and the objectives below will be amended following the review of the needs assessment. The assessment data will be used throughout the 3-day workshop project to make curriculum adjustments centered on the learning needs of the stakeholders (Rubin, Martinez, Chu, 2012).

To begin the workshop, the facilitator will describe the learning objectives. Behavioral objectives are as follows:

1. The learner will identify internal and external motivators to support male caregiver spouses.
2. The learner will define and describe the work purpose of their organization and how they achieve their organizational goals.
3. The learner will identify in what circumstances their agency can assist the male caregiver spouse.
4. The learner will define the principles of Knowles Adult Learning Theory.
5. The learner will assess existing evaluation procedures to incorporate one new evaluation procedure that evaluates for organizational Adult Learning Theory.

6. The learner will articulate confidence to design an organization curriculum using Adult Learning Theory principles.
7. The learners will work as a team to develop a male caregiver spouse curriculum for their agency to assist and support the male caregiver in his caregiver role.

The planned activities for the training workshop will be discussed with the learners; and opportunities for unplanned content will be built into the curriculum design depending on the desired learner need. Strategic teaching and learning activities include group activities related to the learner's organization services for the caregiver/care recipient dyad; interactive discussions; individual organization curriculum design learning activities; peer evaluation of curriculum design and individual consultation services.

The anticipated outcomes are the integration of adult learning theory and knowledge transfer methods into program development and curriculum design for agencies that interface with male caregiver spouses.

Target Audience

The target audience includes individuals who work for agencies that work with male caregiver spouses and their wives. Township and county government personnel, support staff at active adult communities, social workers, religious leaders, home care aides, and medical providers may all find this workshop series useful to their efforts to serve elderly men who are primary caregivers for their wives.

Timeline

This workshop will be presented on three days, separated by two-week intervals, so that the entire series is completed in about one month. Planning for the workshop, including input from local stakeholders, will begin about five months prior to the date of the first workshop. A follow-up review of implementation of workshop ideas will be made about three months following the third workshop. The entire workshop period, from stakeholder planning through workshop evaluation, will last nine months. This lengthy period keeps the topics offered in the workshop present in the minds of service providers to an extent that may facilitate practical change. The timeline of events is depicted in Table A1.

Table A1

Timeline for Implementation of the Supporting the Male Caregiver Spouse *Workshop*

Topic and Time	Task and participants
20 weeks prior to workshop	• Discuss program aims with local stakeholders, via phone, email or face-to-face conversation;. • Secure meeting space on appropriate dates from the sponsoring hospital or other entity; • Apply for refreshment grant through the Office on Aging; • Request names and email addresses of prospective program participants from local stakeholders.
8 weeks prior to workshop	• Send the Needs Assessment form to prospective program participants, and an invitation to attend the workshop; • Invite guest speakers.
6 weeks prior to workshop	• Receive completed Needs Assessment forms; • Analyze needs expressed by prospective participants.
4 weeks prior to workshop	• Confirm participant intentions to attend

(table continues)

Topic and Time	Task and participants
Workshop 1	• Conduct the first 8-hour workshop.
Between-workshop period (2 weeks)	• Program facilitator reviews participant evaluations of Workshop 1 and adjusts to plans for Workshop 2; • Participants revise their agency curriculum for elderly spousal caregiver to incorporate tenets of Adult Learning Theory.
Workshop 2	• Conduct the second 8-hour workshop.
Between-workshop period (2 weeks)	• Program facilitator reviews participant evaluations of Workshop 2 and adjusts to plans for Workshop 3; • Participants revise their agency curriculum for elderly spousal caregiver to respond to men's unique needs.
Workshop 3	• Conduct the final 8-hour workshop.
Week following Workshop 3	• Program facilitator reviews participant evaluations of Workshop 3 and the entire 3-day program.
3 months post workshop	• Distribute first post-workshop evaluation to all participants and stakeholders; • Review evidence of transfer of learning; • Make an interim report to stakeholders.
6 months post workshop	• Distribute second post-workshop evaluation to all participants and stakeholders; • Review evidence of transfer of learning; • Make a final, formal written report to stakeholders, including recommendations for further action.

Budget

Cost to present this series of workshops includes the following:

Room rental. Meeting space will be donated by the sponsoring hospital in its building or donated by the township office or other entity. The anticipated cost for three 8-hour days is $0.

Refreshments and box lunches. Food for participants will be secured through a local catering service at an estimated fee totaling $30 per person per workshop. The anticipated cost for 25 participants for all three days of the workshop series is $2250.

Duplication of handouts and assignment materials. Paper goods needed for the workshop series will be produced through an online discount copy center (e.g., DocuCopies) at an estimated fee totaling $3 per person. The anticipated cost for 24 copies (8 each workshop) for 25 participants is $75.

Honoraria for invited speakers. I shall present the main body of each workshop but at least one topic area expert will be invited to speak at each of the workshops. A small honorarium of $100 will be offered to each of these guest speakers. The anticipated cost for 3 speakers is $300.

The total direct cost to present Supporting the Male Caregiver Spouse: A 3-day Workshop for Service Providers is anticipated to be $2625. These costs could be recovered through a fee of $105 per participant paid by each participant's employing agency. Indirect costs of facilitator time in planning and conducting this event and in making final reports to stakeholders, and of participant time in attending the three workshops are not included in this calculus and are borne by agencies that employ these professionals.

Workshop Plan

This plan for the 3-day workshop includes detailed activities of workshop elements, including a needs assessment, lesson plans for each workshop, teaching materials, and evaluation methodologies. The intended audience for this workshop series includes people who work for agencies from the township, home care agencies, adult day care services, community nurses, physical therapy agencies, transportation services, and meal delivery services.

Needs Assessment

Several weeks before the first workshop, I will gather support from key stakeholders to facilitate the program, including names and email addresses of their employees who might attend the 3-day workshop. Each of these employees and the stakeholders themselves will then be emailed a short survey to determine their level of awareness of the needs of EMSCs and to provide these prospective participants with an opportunity to help shape the workshop content. Prospective participants will also receive an invitation to attend the workshop, along with instructions for sending back the Needs Assessment survey.

When the needs assessments are received, the information provided by prospective participants will be used to fine-tune the planning of workshop sessions. The Needs Assessment survey is presented in Table A2.

Table A2

Workshop Participants Learning Needs Assessment Tool

Supporting the Male Caregiver Spouse: A 3-day Workshop for Service Providers

This 3-day interactive workshop is intended to identify the needs of the male caregiver spouse and assist you in responding to him in that role. You will come away from this workshop with a fuller understanding of Adult Learning Theory, an appreciation for the unique needs of elderly male spousal caregivers, and an individualized curriculum for supporting men as they care for their invalid wives.

This workshop is conducted by me, Stephanie Sexton, RN-BC, MSN. Please help me tailor this experience to you by telling me a bit about your work.

Your name: ____

Your email address: ____

Your agency: ____

Please rate…					
…your current knowledge of the unique needs and point of view of the male caregiver spouse	Expert	Quite a lot	Some	Unclear	Unaware
…your agency's level of interaction with male caregiver spouses	Expert	Quite a lot	Some	Unclear	Unaware

What would you most like to learn with regard to male caregiver spouses?

What are your *organizational needs* related to serving male caregiver spouses?

What are your *own learning needs* related to serving male caregiver spouses?

What would you like this workshop to be sure to include?

Workshop Lesson Plans

Plans for each of the three days of the workshop series are presented here. Course content may be adjusted, based upon the learning needs described through the Needs Assessment survey.

Workshop 1: Introduction to Adult Learning Theory. The plan for the first workshop day includes discussion of Adult Learning Theory, especially with regards to the experience of elderly men. The schedule for the day is presented in Table A3.

Table A3

Schedule for Workshop 1

Time	Topic	Method	Assessment	Resources
8:00 a.m.	Gathering, coffee	Conversation	None	Beverage table
8:30 a.m.	Introduction to the course & each other	Presentation; individual introductions	None	Agenda
9:00 a.m.	Understanding each agency represented, it's purpose and client-base, including elderly men.	Small group exchange, followed by whole-group sharing	Generated list of challenges, with regard to male caregiver spouses	
9:45 a.m.	Introduction to the problem of male spousal caregivers and review of participants' Needs Assessment surveys	Guided discussion	Group consensus regarding the lack of attention to male caregiver spouses and the need for more.	Handout: Needs Assessment Results
10:30 a.m.	Break			

(table continues)

Time	Topic	Method	Assessment	Resources
10:45 a.m.	Principles of Adult Learning Theory, with emphasis on men's prior knowledge of caregiving and caregiving as a social role	Power Point presentation	Group discussion	Laptop and projector
Noon	Lunch			
12:45 p.m.	The experience of male caregiver spouses: Results from the Project Study	PowerPoint presentation	Group discussion	Laptop and projector; handout
1:45 p.m.	View Cowan Concert at Mayo Clinic from 2008 and 2010, posted on YouTube	Video presentation	Group discussion of lived experience of caregiver/care-recipient dyads	Laptop and projector with Internet access
2:15 p.m.	Break			
2:30 p.m.	AARP report on Caregiving	PowerPoint	Small group discussion of key motivations of male caregiver spouses	Laptop and projector; handout
3:30 p.m.	Reflection on ways to support male caregiver spouses	Guided conversation	Individual lists	
3:45 p.m.	Workshop 1 evaluation and assignment for Workshop 2		Assignment for Workshop 2: log interactions with and reflections about male caregiver spouses	Evaluation forms; assignment handout
4:00 p.m.	Adjourn			

Workshop 2: Needs of the Male Caregiver Spouse. The second workshop occurs after a break of two weeks, during which participants are expected to have kept a log of their observations of and reflections about male caregiver spouses. The content of the second workshop includes consideration of the unique needs of EMSCs. The schedule for the day is presented in Table A4.

Table A4

Schedule for Workshop 2

Time	Topic	Method	Assessment	Resources
8:00 a.m.	Gathering, coffee; Review of Workshop 1 contents, with any thoughts or additions participants care to add. Presentation of the day's agenda.	Conversation	None	Beverage table; agenda
8:45 a.m.	What you learned from the men you observed.	Small group discussion of log assignment, followed by whole-group sharing and synthesis of results.	List of observations, reflections, and insights about EMSCs	White board or flip chart
10:00 a.m.	Connecting observed needs with Adult Learning Theory.	Group discussion	Annotations added to list of challenges created above	White board or flip chart
10:30 a.m.	Break			

(table continues)

Time	Topic	Method	Assessment	Resources
10:45 a.m.	Planning for action: Dyads apply principles of Adult Learning Theory to instance from their observation logs.	Small group work	Written artifact	Space for working in pairs without disruption or crowding
11:30 a.m.	Dyads combine into groups of four to share their thoughts and make adjustments	Small group work	Written artifact	Space for working together in small groups.
Noon	Lunch			
12:45 p.m.	*Experience 12 Minutes In Alzheimer's Dementia* - YouTube. Aug 21, 2012	Video presentation, followed by group discussion	Group discussion	Laptop and projector
1:30 p.m.	The learners review their agency policies related to caregiver spouses, with attention to men and men's needs	Guided discussion	Group discussion of lived experience of caregiver/care-recipient dyads	Laptop and projector with Internet access
2:15 p.m.	Break			
2:30 p.m.	Sensory deprivation simulation, in which learners will experience challenges of aging.	Simulation exercise	Group experience with individual participation	Goggles Gloves Pebbles Color charts Newspaper
3:30 p.m.	Services men use, services men need	Review of service use/need information from the Project Study	PowerPoint	handout

(table continues)

Time	Topic	Method	Assessment	Resources
3:45 p.m.	Workshop 2 evaluation and assignment for Workshop 3		Assignment for Workshop 3: log service use by male caregiver spouses and service provisions or lack of services to meet men's needs.	Evaluation forms; assignment handout
4:00 p.m.	Adjourn			

Workshop 3: Providing for the Male Caregiver Spouse. The third workshop occurs after another break of two weeks, during which participants are expected to have reviewed services provided for EMSCs and the extent to which those caregivers use available services. The content of the third and final workshop includes development of action plans specific to each agency or organization and its clientele. The schedule for the day is presented in Table A5.

Table A5

Schedule for Workshop 3

Time	Topic	Method	Assessment	Resources
8:00 a.m.	Gathering, coffee; Review of Workshop 2 with any thoughts or additions participants care to add. Presentation of the day's agenda.	Conversation	None	Beverage table; agenda

(table continues)

Time	Topic	Method	Assessment	Resources
8:45 a.m.	What discovered about services provided for male spousal caregivers and what services men actually use.	Small group discussion of log assignment, followed by whole-group sharing and synthesis of results.	List of observations, reflections, and insights about services for EMSCs	White board or flip chart
9:30 a.m.	Connecting observed needs and service use with Adult Learning Theory (ALT).	Group discussion	Analysis of connection of service provisions to needs and presentation of services to ALT.	White board or flip chart
10:30 a.m.	Break			
10:45 a.m.	Facilitating Knowledge Transfer within the organization	Identify Knowledge Transfer strategies in group game	Work together in the Knowledge Transfer Game	Laptop and projector
11:30 a.m.	Planning for learning	Individual thought and writing	Sketch of curriculum for male caregivers	
Noon	Lunch			
12:45 p.m.	Writing curricula for use with either male spousal caregivers or with employees/ subordinates	Individually or pairs or small groups as fits each participant and situation.	Curriculum products presented as posters or charts	Large chart paper; fine-line markers
2:15 p.m.	Break			
2:30 p.m.	Share curricula with the entire group, in a poster session followed by conversation.	Whole-group sharing	Feedback shared and ideas fine-tuned.	

(table continues)

Time	Topic	Method	Assessment	Resources
3:30 p.m.	Commitment to action; goals; timeline	Individuals or work groups create a plan of implementation of curricula, with timeline	Timelines created	
3:50 p.m.	Workshop 3 evaluation	Announce progress check in 3 months.		Evaluation forms
4:00 p.m.	Adjourn			

Evaluation of the Project

This project will be evaluated at five points. Each of the three workshops will be evaluated by participants, using the form presented in Table A6. Results of each evaluation will be used to help plan subsequent sessions and, in the case the Workshop 3, the interactions with participants at the 3-month and 6-month reviews.

Table A6

Workshop Evaluation Form

Supporting the Male Caregiver Spouse: A 3-day Workshop for Service Providers

Workshop Evaluation

Workshop 1 2 3 (please circle)

1. What was the most important or interesting thing you learned in today's session about Adult Learning Theory?
2. What was the most important or interesting thing you learned in today's session about elderly male spousal caregivers?
3. What element of today's session has been least successful for you? Why?
4. What will you do in the next two weeks as a result of what you learned today?
5. What suggestions do you have for future presentations of this workshop?

In addition, the outcome of participants' plans for curriculum change and service upgrades, made in Workshop 3, will be reviewed at two points: three months and six months after Workshop 3. At that time, each participant and each stakeholder (if not a workshop participant) will be sent an email survey using Survey Monkey, as illustrated in Table A7.

Table A7

Post workshop Transfer-of-Learning Survey

Supporting the Male Caregiver Spouse: A 3-day Workshop for Service Providers

Three-[Six-]Month Follow-up Survey

Please help me determine the success of the 3-day workshop, Supporting the Male Caregiver Spouse, that you attended three [six] months ago. Answer the following questions as well as you can. Your answers will be anonymous.

1. How would you rate your knowledge today of the unique needs and point of view of the male caregiver spouse? I feel…
   Expert in this
   Know quite a lot
   Know some
   I feel unclear
   I am unaware of these needs and point of view

2. How would you rate your agency's (or company's or organization's) level of interaction with male caregiver spouses? My organization is
   Expert in this
   Knows quite a lot
   Knows some
   Is unclear on this
   Is unaware of the needs and point of view of male caregiver spouses

3. What changes did you make in your own professional practice with regard to male spousal caregivers in the months since the 3-day workshop?

4. What changes did your organization make in its approach to male spousal caregivers in the months since the 3-day workshop?

5. What effect have your efforts had on male spousal caregivers that you and your organization serve?

(table continues)

6. What are your plans for future changes or adjustments in your services for male spousal caregivers?

7. What have been your biggest sources of frustration and challenge in your efforts to better serve male spousal caregivers?

8. What more would you like to know about adult learning theory or male spousal caregivers?

Thank you very much!

Interim and Final Reports

Following receipt of the surveys at three and six months following the 3-day workshop, results will be collated and described in an Interim (3-months following) and Final (6-months following) report, which will be distributed to stakeholders. The intention in creating and distributing these reports is to provide additional insight to stakeholders into organizations’ service to EMSCs and to continue to inspire organizational action on these caregivers’ behalf. These reports serve as the final evaluation of this project and its power to positively influence social change.

Appendix B: Consent Form

CONSENT FORM

You are invited to take part in a research study intended to learn more about the experiences of older men who care for an ill or disabled wife. You were chosen for the study because you self-identified as an older man who cares for an ill or disabled wife. This form is part of a process called “informed consent” to allow you to understand this study before deciding whether to take part.

This study is being conducted by a researcher named Stephanie Fitzsimmons Sexton, who is a doctoral student at Walden University and a geriatric nurse practitioner in Central New Jersey.

Background Information:

The purpose of this study is to learn more about the challenges felt by older men who serve as caregivers for their wives, the support they feel they need in their role as caregivers, and also the supports men currently use to assist them. It is hoped that a greater understanding of men’s experiences in the caregiver role will help us to provide better, more helpful services.

Procedures:

If you agree to be in this study:

- It is anticipated it will take 30 minutes to complete the 4 short survey instruments , which are included in this packet;
- You may skip answering any questions on the four survey instruments and proceed on to the next question.
- Return the four completed surveys in the enclosed envelope.

Voluntary Nature of the Study:

Your participation in this study is voluntary. This means that everyone will respect your decision whether or not you want to be in the study. No one in our community or at Walden University will treat you differently if you decide not to be in the study. If you decide to join the study now, you can still change your mind during the study. If you feel stressed during the study you may stop at any time.

Risks and Benefits of Being in the Study:

There is minimal possibility of psychological stress because of the sensitive nature of the questions asked on some of the survey instruments. The benefits may be in identifying new sources of support that are available to you to help you in your caregiver role or to help you increase your own well-being and satisfaction.

Compensation:

There will be no compensation for participating in this study.

Confidentiality:
Any information you provide will be kept confidential. The researcher will not use your information for any purposes outside of this research project. In order to protect their privacy no signatures are being collected and the completion of the survey will indicate your consent, if you choose to participate. Also, the researcher will not ask for or include your name or anything else that could identify you in any of the surveys. All surveys and forms will be kept in a locked file which will only be accessible to the primary investigator.

Contacts and Questions:
You may ask any questions you have now. Or if you have questions later, you may contact the researcher via telephone (732) 241-8807, or email at stephanie.sexton@waldenu.edu. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Her phone number is 1-800-925-3368, extension 3121210. Walden University's approval number for this study 07-30-14-0149191.

This Consent form is yours to keep for your records.

Statement of Consent:

I have read the above information and I feel I understand the study well enough to make a decision about my involvement. By submitting the completed surveys, I am agreeing to the terms described above.

Appendix C: Background Information Sheet

1. How many years have you and your wife been married? (Or been living together?)

________ Years

2. Do you and your wife live together at your home?

_______Yes _______No. My wife lives at a care facility.

3. What is your age _________years?

4. Do you live in an active adult community in Monroe Township? (Circle)Yes No

5. What illness or disabling condition does your wife have?

____

Thank you! Please continue with the next survey.

Appendix D: Zarit Burden Interview

INSTRUCTIONS: The following is a list of statements, which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way: never, rarely, sometimes, quite frequently, or nearly always. There is no right or wrong answers.

1. Do you feel that your wife asks for more help than she needs?

   Never Rarely Sometimes Quite Frequently Nearly Always

2. Do you feel that because of the time you spend with your wife that you don’t have enough time for yourself?

   Never Rarely Sometimes Quite Frequently Nearly Always

3. Do you feel stressed between caring for your wife and trying to meet other responsibilities for your family or work?

   Never Rarely Sometimes Quite Frequently Nearly Always

4. Do you feel embarrassed over your wife’s behavior?

   Never Rarely Sometimes Quite Frequently Nearly Always

5. Do you feel angry when you are around your wife?

   Never Rarely Sometimes Quite Frequently Nearly Always

6. Do you feel that your wife currently affects your relationship with other family members or friends in a negative way?

Never Rarely Sometimes Quite Frequently Nearly Always

7. Are you afraid what the future holds for your wife?

Never Rarely Sometimes Quite Frequently Nearly Always

8. Do you feel your wife is dependent upon you?

Never Rarely Sometimes Quite Frequently Nearly Always

9. Do you feel strained when you are around your wife?

Never Rarely Sometimes Quite Frequently Nearly Always

10. Do you feel your health has suffered because of your involvement with your wife?

Never Rarely Sometimes Quite Frequently Nearly Always

11. Do you feel that you don’t have as much privacy as you would like, because of your wife?

Never Rarely Sometimes Quite Frequently Nearly Always

12. Do you feel that your social life has suffered because you are caring for your wife?

Never Rarely Sometimes Quite Frequently Nearly Always

13. Do you feel uncomfortable about having friends over, because of your wife?

    Never Rarely Sometimes Quite Frequently Nearly Always

14. Do you feel that your wife seems to expect you to take care of her, as if you were the only one she could depend on?

    Never Rarely Sometimes Quite Frequently Nearly Always

15. Do you feel that you don’t have enough money to care for your wife, in addition to the rest of your expenses?

    Never Rarely Sometimes Quite Frequently Nearly Always

16. Do you feel that you will be unable to take care of your wife much longer?

    Never Rarely Sometimes Quite Frequently Nearly Always

17. Do you feel you have lost control of your life since your wife’s illness?

    Never Rarely Sometimes Quite Frequently Nearly Always

18. Do you wish you could just leave the care of your wife to someone else?

    Never Rarely Sometimes Quite Frequently Nearly Always

19. Do you feel uncertain about what to do about your wife?

    Never Rarely Sometimes Quite Frequently Nearly Always

20. Do you feel you should be doing more for your wife?

Never Rarely Sometimes Quite Frequently Nearly Always

21. Do you feel you could do a better job in caring for your wife?

Never Rarely Sometimes Quite Frequently Nearly Always

22. Overall, how often do you feel burdened in caring for your wife?

Never Rarely Sometimes Quite Frequently Nearly Always

Thank you! Please continue with the next survey.

Appendix E: Multi-dimensional Scale of Perceived Social Support

Instructions: I am interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

1. There is a special person who is around when I am in need.

Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree

2. There is a special person with whom I can share joys and sorrows.

Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree

3. My family really tries to help me.

Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree

4. I get the emotional help and support I need from my family.

Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree

5. I have a special person who is a real source of comfort to me.

Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree

6. My friends really try to help me.

Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree

7. I can count on my friends when things go wrong.

Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree

8. I can talk about my problems with my family.

Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree

9. I have friends with whom I can share my joys and sorrows.

Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree

10. There is a special person in my life who cares about my feelings.

Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree

11. My family is willing to help me make decisions.

Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree

12. I can talk about my problems with my friends.

Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree

Thank you! Please continue with the next survey.

Appendix F: Support Services in Your Area

Please check all services *that you are currently using* in caring for your wife.

__________ Adult Day Care
__________ Home Care
__________ Community Nurse within the Community
__________ Physical Therapy in the home
__________ Physical Therapy at an Office Location
__________ Physician who makes home visits
__________ Township Office on Aging Services
__________ Caregiver Support Group
__________ Counseling
__________ Meal Delivery Service
__________ Online Food orders with home delivery
__________ Transportation Services
__________ Cleaning Service

Please check all services that you would consider using in your home but that you are NOT currently using.

__________ Adult Day Care
__________ Home Care
__________ Community Nurse within the Community
__________ Physical Therapy in the home
__________ Physical Therapy at an Office Location
__________ Physician who makes home visits
__________ Township Office on Aging Services
__________ Caregiver Support Group
__________ Counseling
__________ Meal Delivery Service
__________ Online Food orders with home delivery
__________ Transportation Services
__________ Cleaning Service

Why do you choose *not* to use any of these services?

What additional service would be helpful to you?

Thank you! Please check to see that you have completed all four surveys and have signed the consent form. Then place all the materials in the envelope that came in your packet, seal the envelope, and drop it in a mailbox or leave it for your postal carrier to pick up.

Your help in this research study is very much appreciated. Best wishes to you and your wife.

Appendix G: Welcome Message

Thanks so much for your interest in my research study. I want to know more about your experiences in your role as caregiver for your wife. I very much appreciate your time and attention to the materials contained in this packet.

First, please read through the consent form, which tells you more about this study. Next, please complete the four surveys. These are a Background Information Sheet, the Zarit Burden Interview, the Multi-dimensional Scale of Perceived Social Support, and a checklist of Support Services in Your Area. You can do these in any order you like. As you complete each one, slide it into the return envelope.

I believe it will take you about half an hour to complete all the materials in the packet. When all are finished, make certain everything is in the return envelope, seal the envelope, and put it in the mail. The envelope already has postage on it.

If you would like to seek professional assistance to help you cope with your duties as a male caregiver spouse, please contact Jewish Family Services, the community nursing office located within your clubhouse or the Township Office on Aging. All of these offices can provide you with assistance or refer you to a caregivers support group.

Thank you again for helping me. You are helping men like yourself in our area, since the information you share will help me and others know better how to help you.

Sincerely,

Stephanie

Stephanie Fitzsimmons Sexton

Appendix H: Newspaper Ad/ Flier Information

Volunteers Needed for an Important Research Study

Is your wife ill or disabled?

- Do you assist your wife with house cleaning, meal preparation or personal care because she needs assistance with these tasks?
- Do you do tasks for your wife that she once did on her own, because she is no longer able to do this herself?

If so, then you are invited to participate in a research study of the experiences of men who serve as caregivers for their wives. I am interested in finding out about the challenges you face and in finding ways to serve you better.

Participation is easy.

- You will be asked to complete four short surveys. These surveys can be completed at home and returned by mail.
- Only about 30 minutes of your time is required.
- Your identity and your wife's identity will be kept completely confidential. No names are asked for on any of the survey forms.

To be part of this important research study, contact

Stephanie Fitzsimmons Sexton

(732) 241-8807 or at *stephanie.sexton@waldenu.edu*.

Help us understand the challenges you face and find ways to serve you better.