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Support for Caregivers after the Loss of the Caregiving Role

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Support for Caregivers after the Loss of the Caregiving Role

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Abstract

By 2030, it is expected that older adults will account for one out of every five Americans (Centers for Disease Control and Prevention, 2013). With older adults living longer, and living with chronic illnesses and cognitive impairments, comes a greater demand for caregivers and services to support those in this role. The stress of caregiving, including its negative impact on physical, social and mental well-being, is well documented in the literature (Toseland, 1990). Formal services to support the caregiver and address the negative effects are widely available. Fewer studies have examined the need for services following the loss of the caregiving role. This study explored the need for and availability of support services as caregivers transition from an active caregiving role to life after the loss of this role. Through semi-structured interviews of nine professionals from agencies providing federally-funded caregiver support programs and services several themes emerged. The themes related to Caregivers were: identifying as a caregiver and transitioning out of that role, importance of addressing physical and mental health needs and focusing on the strengths of caregivers. In addition, value of planning for the future, linkage to and acceptance of support, time of transition, and urgency and innovation were themes that emerged related to support services. The findings indicate a need for and the value of increased support services for caregivers after the loss of the caregiving role. Implications for social work practice, policy and research are also highlighted.

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Support for Caregivers after the Loss of the Caregiving Role

The graying of America brings with it many opportunities and challenges. By 2030, it is expected that older adults, defined as those over the age of 65, will account for one out of every five Americans (Centers for Disease Control and Prevention, 2013). Longer life expectancy is due primarily to advances in health care. Major causes of death have shifted from preventable, communicable diseases to chronic illnesses greatly impacted by lifestyle choices and environmental factors (CDC, 2013). With older adults living longer, and living with chronic illnesses and cognitive impairments, the demand for persons needing formal and informal caregivers significantly increases. Three-quarters of older adults with physical or cognitive impairments rely on caregiving assistance of friends and family (McInnis-Dittrich, 2014). According to the Family Caregiver Alliance (2012), more than 65 million Americans care for a chronically ill or disabled loved one. Of these, sixty percent are women (primarily spouses or daughters) and one-third are an older adult themselves (McInnis-Dittrich, 2014).

Caregiving can be a rewarding yet challenging experience. In a study of caregivers of individuals with Alzheimer's disease, eighty one percent of caregivers reported both strains and gains of the caregiving role (Sanders, 2005). Informal caregivers play a key role in providing care that allows the care recipient to remain in his or her own home as long as possible. Care provided in the home is less costly than care in assisted living or long-term care facilities. Caregiver burden is one of the most widely investigated topics in the literature on caregiving (Bastawrous, 2013). Caregiving is often a 24- hour job without a break and without formal training. A caregiver wrote about the challenge of providing care for her husband with Parkinson's Disease, "many

long-term caregivers do live in a bubble; for twenty-four hours a day, a caregiver can never turn away from the ultimate responsibility for the health and life of a person he or she loves" (Toth, 2014). The attention is focused on the needs of care-recipient while the physical, social and psychological needs of the caregiver are often neglected.

This stress of caregiving is well documented in the literature which notes the negative effects on physical, social and mental well-being of the caregiver (Toseland, 1990). Formal support services that mutually benefit the care recipient and caregiver have become more abundant in the past thirty years. Respite care, adult day programs, psycho-educational support groups, home health care, geriatric care management and hospice provide cost-effective interventions for those who are the in need of additional support in a caregiving role. Another important source of support is that of informal systems, such as family, friends, neighbors and faith communities. Tapping into these formal and informal support systems may ease the stress and burden of the caregiving role while preventing social isolation, depression and exhaustion. Utilizing these systems may also prevent the need for more costly levels of care such as assisted living, memory care or nursing home placement.

Much of the literature focuses on caregiver support while in the caregiving role while less is known about the adaptation of caregivers after bereavement. It is estimated that professional help for mental health concerns may be required in one third of all bereavements (Brazil, Bedard & Willison, 2002). The mental health of the caregiver has been shown to have an influence on one's physical health (Chang, Chiou & Chen, 2010). Caregivers have often neglected their own health needs due to the overwhelming demands of caring for another and may face health issues of their own. Adapting to

changes in one's roles is another task during bereavement as the caregiver redefines relationships and adjusts to the new normal after the loss of the caregiving role due to the death or relocation of the care recipient.

Multiple studies have shown that only 30% of caregivers use bereavement services in the year following the loss of the caregiving role (Cherlin, Barry, Prigerson, Schulman-Green, Johnson-Hurzeler, Kasl & Bradley, 2007, Brazil, et al., 2002, & Bergman, Haley & Small, 2011). Understanding who uses the services and why, barriers to participation and gaps in services will assist in developing an infrastructure for a continuum of caregiver support services, from initiation of the caregiving role to post-loss. As the population of older adult continues to grow, the need for caregiver support services, during and after the caregiving role, is going to increase substantially.

The purpose of this study was to explore the availability of and need for on-going support for caregivers after the loss of the caregiving role. Through interviews of professionals, the researcher explored current programs and services, unmet needs, barriers to participation and future direction of support services for caregivers as they transition from the caregiving role.

Literature Review

Definitions

What constitutes a caregiver or care recipient differs and often is not clearly defined in the literature. This presents limitations and challenges in generalizing results to the larger population. Very few studies provided a clear definition of a caregiver and relied on the reader to have a general understanding of the term. Often what is discussed is the chronic condition of the care recipient for which the caregiver is providing support, such as Alzheimer's disease, or dementia, cancer or stroke.

A family caregiver, also known as an informal caregiver, is one who provides care without financial compensation (Bastawrous, 2013). Other factors used to define a family caregiver are the type of assistance provided (such as personal cares or emotional support) and the extent of assistance, meaning hours of care provided (Bastawrous, 2013). Many studies have focused on spouses as family caregivers; however with the changing demographics, adult children are now recognized as a significant resource of family caregiving (Bastawrous, 2013).

The definition of caregiver has also been broadened to include anyone who has a significant personal relationship with and provides assistance for someone with a life-threatening or chronic condition (Blum & Sherman, 2010, Hudson, Remedios, Zordan, Thomas, Clifton, Crewdson, Hall, Trauer, Bolleter, Clarke, & Bauld, 2012). This incorporates caregivers who are non-family such as partners, friends or neighbors. A final definition in the literature is the person, not in a professional relationship, most familiar with the state of health and care needs of the patient (Rebollo, Alonso, Ramon, Vilagut, Santed & Pujol, 2005).

Primary and secondary caregivers are also referenced in the literature. The distinguishing factor between primary and secondary is typically the level of responsibility, the amount of time devoted to delivering cares or the location of residence of the caregiver (Blum & Sherman, 2010). For example a primary caregiver is one who provides the most amount of unpaid care and makes the majority of day-to-day decisions on the caregiver's behalf (Cheng, Lau, Mak, Ng, Lam, Fung, Kwok, Lee, 2012).

In addition to informal caregivers, formal caregivers, defined as "a provider with a formal service system, whether paid worker or volunteer" also provide services to care recipients (Family Caregiver Alliance, 2012). While there are similarities such as burden and stress, between these two groups of caregivers, resources and training may be significantly different. Informal or family caregivers will be the focus of this study.

Care recipient was not defined in any of the literature reviewed for this study, possibly because one may have an assumed understanding of this term. For purposes of this study the care recipient was defined as the person who is receiving care for a serious health condition and is unable to provide self-cares without assistance.

Demographics of Caregivers

In the United States, over 44 million adults are family caregivers caring for someone over the age of 50 (Family Caregiver Alliance, 2012). Of these, more than half are older than age 75 themselves (Blum & Sherman, 2010). Two thirds of family caregivers are women (Family Caregiver Alliance, 2012). Spouses provide more total hours of care than adult children (Labrecque, Peak & Toseland, 1992). It is more common for spouses to experience the caregiving role in older adulthood of which the developmental roles are different in this late-life stage. Many are retired with adult

children. For adult children and daughters in particular, taking on the role of family

caregiver often happens at mid-life (Bernard & Guarnaccia, 2003). Coined the sandwich

generation, a dual role exists of caregiving one's parent and children at the same time,

often while juggling work, home and family responsibilities (Murphy, Nalbone, Wetchler

& Edwards, 2015).

Family caregiving increases among certain racial, ethnic or other minority groups.

Rates are higher among Asian-American, African-American and Hispanic-Americans

attributable to valuing family and strong kinship (McInnis-Dittrich, 2014). Less

information about those who identify as Lesbian, Gay, Bisexual or Transgender (LGBT)

in the caregiver role was found in the literature. In one study of the informal caregiving

experience of midlife and older LGBT adults, Croghan, Moone & Olson (2014) found

that non-relatives were more likely to serve in the caregiving role for this population.

These non-relatives may be part of what is considered "chosen family" for the LGBT

person - those with whom one is in close relation yet often not a biological or legal

relative.   Caregivers who are non-relatives may experience greater stress due to limited

availability of caregiver support services. Another factor that may increase caregiver

burden for the LGBT caregiver is the reluctance to disclose their sexual orientation or

seek services for fear of discrimination or receiving poor quality services (Croghan, et al.,

2014). A study of older adults indicated that more than 20% of LGBT persons do not

disclose their sexual or gender orientation to their health care provider and 13% have

been denied health care or received inferior care because of their identified orientation

(CDC, 2013).

Caregiver Burden and Gain

The majority of caregivers report both burden and gain in their caregiving role. In a study of those caring for an individual with Alzheimer's disease, eighty one percent reported experiencing both strains and gains, with less than one in five reporting only experiencing strains (Sanders, 2005). Caregiver burden is described as negative physical, emotional and psychological impact on the caregiver (Sanders, 2005, Chang, et al., 2010, Bastawrous, 2013). Research using a strengths perspective has demonstrated that experiencing positive gains from a caregiving role is common with 55 - 90% of caregivers reporting such outcomes The term gain is defined as "the extent to which the caregiving role is appraised to enhance an individual's life" (Sanders, 2005).

Caregiver burden comes from many different sources. One study identified the strain or burden of caregiving related to three themes - worries and uncertainties, balancing multiple demands and overwhelmed with care. Limited control of the circumstances, a lack of understanding of where the care recipient was in the disease process, continual decline in health of the care recipient and feelings of fatigue were underlying factors (Sanders, 2005). Adult daughters in a caregiving role may experience more caregiver strain, and related depression and anxiety, because of the multiple simultaneous demands of parenting, family and employment (Bernard & Guarnaccia, 2003).

Caregiver burden is strongly influenced by the health status of both the care-recipient and the caregiver (Chang, et al., 2010, Bastrawrous, 2013). According to the Alzheimer's Association, sixty percent of those caring for someone with Alzheimer's or dementia rate the stress involved in the caregiving role as high; forty percent of these

caregivers suffer from depression (Alzheimer's Association, 2015). The health care costs of Alzheimer's caregivers themselves are astronomical, reaching $9.7 billion in 2014. Often caregivers put off their own health care due to lack of time, exhaustion and guilt. Studying the relationship between mental health, physical health and burden, researchers found that mental health had a stronger effect on physical health than did burden (Chang, et al., 2010). A concern raised in the literature is that while caregiver burden is one of the most commonly researched topics, caregiver burden is not always clearly defined or framed conceptually in studies (Bastrawrous, 2013).

Caregiver gains center around the caregiver's feelings about themselves and their ability to perform a task first thought of as incapable of doing. Caregivers report finding satisfaction that they can be there for a loved one (Ebenstein, 2008). Positive outcomes center around the theme of gratification and satisfaction. Several studies have shown that caregivers report feeling needed, a sense of purpose and enjoyment from companionship with the care recipient as gains of the caregiving role (as cited in Koerner, Kenyon & Shirai, 2009). Sanders (2005) found perceived gains related to spiritual growth and increased faith, personal growth, and feelings of mastery and accomplishment. The gains often were transferrable to other areas of the caregiver's life (Sanders, 2005).

Which caregivers experience gains? Studies have shed some light on the personal characteristics of caregivers who experience these gains. Findings show that four personality characteristics may be linked to caregiver gain - low neuroticism, high extroversion, conscientiousness and agreeableness (Koerner, et al., 2009). Two interpersonal factors receiving attention in the literature are social support and quality of pre-caregiving relationship between the caregiver and care-recipient (Koerner, et al.,

2009). This particular study indicated a correlation between agreeableness, extroversion and social-emotional support from one's spouse/partner and experiencing caregiver gains. More studies are warranted as the potential gains may shield against the negative outcomes or burden of caregiving.

Caregiver Support Groups

Services to reduce caregiver burden include caregiver support groups and respite care. While adult day programs, home health care, geriatric care management and hospice care target the needs of the care recipient, they are also of benefit to the caregiver. Many studies of caregiver support groups have been conducted and the subsequent findings are of value when considering caregiver health while in the caregiver role, as well as after the loss of it.

The most widely studied evidence-based group interventions with the older adult population are caregiver support groups (Pandya, 2010). These psycho-educational groups offer emotional support and specific information useful in the caregiving role. Normalizing, acknowledging and expressing feelings are central to the intent of the group (McInnis-Dittrich, 2014). Preventing isolation and connection to support networks and resources are also goals of caregiver support groups.

Studies of the efficacy of caregiver support groups have demonstrated positive results in the areas of mobilizing support networks, utilizing coping resources and reducing subjective burden (Toseland, 1990, Labrecque, Peak & Toseland, 1992). The long term effectiveness of support groups was similar regardless if the group was peer-led or professionally led; both showed positive outcomes related to support and coping resources (Toseland, 1990). Despite the positive results of these studies, Labrecque, Peak

and Toseland (1992) found there was no improvement in caregiver depressive symptoms

and the caregiver's own health status declined one year later. The literature indicates

support groups are most effective in providing education on the nature of the illness,

connection to community resources and peer support and less likely to meet the

emotional needs of the participants (Monahan, 1994).

A study of factors affecting use of caregiver support groups showed greater

attendance of those who were older, who had a secondary informal caregiver providing

care or who had significant health problems. Those who were caring for someone with

Alzheimer's and those reporting a higher level of burden were also more likely to attend

(Monahan, Greene & Coleman, 1992). Monahan, et al., (1992) found caregivers whose

care recipient transitioned to a nursing home or died were less likely to attend group.

Virtual support groups have been studied to determine the feasibility of delivering

interventions via the internet. In a 2006 study, ninety percent of caregivers reported

positive benefits from participating (Marziali, Damianakis & Donahue, 2006). These

findings may prove valuable in determining effective ways to reach caregivers after the

loss of the caregiving role and/or during bereavement.

Loss of Caregiving Role

What do caregivers need to prepare for the loss of the caregiving role? While

several studies have been conducted to answer that question, most have focused on

preparing the caregiver for the death itself, rather than bereavement. One study found

that caregivers would be better prepared "if the uncertainty that surrounds end-of-life

caregiving is managed via better communication" (Hebert, Schulz, Copeland & Arnold,

2009). Uncertainty was categorized as four types: medical - the need for information

about prognosis, practical - wills, estates or other financial issues, psycho-social - altered

family relationships as a result of the illness or religious/spiritual - finding meaning in the

loss (Hebert, et al., 2009). Communication, what is said and how it is said, was

determined to be of primary importance in preparing caregivers for bereavement (Hebert,

et al., 2009). Blum and Sherman (2010) also noted the importance of advanced

knowledge and recognition of transitions in giving caregivers an opportunity to

anticipate, prepare and respond accordingly with the ultimate transition being from life to

death of the care recipient.

Grief and Loss

        Caregivers experience a multitude of losses - the loss of a partner, parent or close

relation, identity, time, privacy, leisure, social life, financial status, control and dreams.

For those caring for a person with Alzheimer's or dementia the grief may come in waves

as the caregiver continually adjusts to changes in cognitive function and health status.

Often referred to as ambiguous loss, the caregiver grieves first the psychological death of

the person they once knew and later the biological or physical death (Hooyman &

Kramer, 2006). Holtslander & Duggleby (2010) noted loss within three contexts for

older women caring for a spouse with advanced cancer- intrapersonal (losing a part of

yourself), interpersonal (striking out alone) and community/societal (finding my way).

This study also indicated the psychosocial context of each individual determines how

they will be affected and what supports will be valuable during bereavement.

        Grieving and emotional distress most commonly occurs with the death of the care

recipient but also may be experienced if and when long-term placement in a skilled care

facility is needed. Most care recipients wish to remain in their home as long as possible

and most caregivers do everything in their power to keep their loved one at home

(Ebenstein, 2008). Guilt for abandoning their care recipient, along with the loss of

admiration from others for their tireless caregiving efforts, may accompany the feelings

of grief caregivers may experience in these situations.   While there is much literature

about this type of role change for the caregiver, this study focuses on the loss of role due

to death.

The death of a care recipient may bring a sense of relief and enhanced well-being

for caregivers, especially for those who have been in the caregiving role for an extended

period of time (Hooyman & Kramer, 2006). Spirituality may serve as a source of

comfort as well as a positive coping strategy following a death of a care recipient.

Spiritual growth and increased faith have also been noted as gains in the literature

regarding the positive outcomes of caregiving (Sanders, 2005). The literature highlights

other benefits from bereavement, grief and loss. Personal growth, positive changes in

self-view and reprioritization of life values have been documented in the literature (Kim,

Carver, Schulz, Lucette & Cannady, 2013). These benefits were less likely to occur in

non-spousal caregivers who had greater caregiving stress due to multiple roles and

spousal caregivers with limited social support.

Financial Concerns

Uncertainty around a caregiver's financial future is another concern related to the

loss of the caregiving role. Practical issues such as estate planning, completing wills and

spend down for eligibility of government assistance are at the forefront as the caregiving

role is lost due to long-term care placement or death of a care recipient. Loss or change

of income and/or benefits puts added pressure on the caregiver. In one study of bereaved

caregivers, 45% expressed financial concerns three months post-bereavement

(Holtslander & Duggleby, 2010). One study suggested women who are caregiving for

male spouses may experience greater financial strain due to care recipient's loss of

income from prolonged illness and high cost of medical care (Gilbar & Ben- Zur, 2002).

Hebert, et al., (2009) found that communication regarding financial uncertainty is equally

important as medical, psychosocial and spiritual issues surrounding death in terms of

improving caregiver well-being during times of loss. Receiving assistance for financial

concerns may ease caregiver burden by reducing psychological strains such as anxiety,

insomnia and depression (Skalla, Smith, Li & Gates, 2013).

Health Status

Physical and mental health is impacted by the caregiving role. Depression and

anxiety have been reported in up to 44% of caregivers and physical health measures are

below population norms in approximately 50% (Hudson, et al., 2012). Brazil, et al.,

(2002) noted caregivers who reported poor physical health during caregiving had a poorer

mental health status during bereavement. This study also found that caregivers had better

health outcomes when their care recipient died in the home rather than in an institutional

setting. Several studies demonstrated a difficult caregiving experience equated with

greater physical and mental health issues in bereavement (Brazil, et al., 2002, Holtslander

& Duggleby, 2010), in particular older women who lost a spouse (Hooyman & Kramer,

2006, Rebollo, et al., 2005, Gilbar & Ben-Zur, 2002). One study found the intensity of

association between the death of a close elderly relative and emotional health was related

not only to being a spouse or child of the deceased, but also to a low educational level

(Rebollo, et al., 2005).

Bereavement Supports

Much of the literature focuses on preparing caregivers for the death of the care

recipient not bereavement (Hebert, et al., 2009). The bereavement needs of caregivers

are unique to each individual and are dependent upon multiple factors. About one in

three of all major bereavements result in problems where professional help is

recommended (Brazil, et al., 2002). Bergman, Haley and Small (2010) found the three

most common reasons for caregiver utilization of bereavement services were depressive

symptoms, anxiety and complicated grief. One study showed that caregivers continued to

have higher rates of depressive symptoms and anxiety disorder three years after

bereavement (Bodnar & Kiecolt-Glaer, 1994). This study also indicated that recurrent

depression may be linked to smaller support networks of caregivers and rumination about

the former caregiving role.

Minimal evidence exists to support routine intervention with all bereaved

caregivers; rather, it is recommended a preliminary plan be developed based on the needs

of the caregiver, then monitored and adjusted throughout bereavement (Hudson, et al.,

2012). Personalizing bereavement supports to reflect individuals differences in

caregiving stress and caregiver esteem will help caregivers find meaning in the loss (Kim,

et al., 2013). Findings suggest programs should also be designed to meet the differing

needs of spousal versus non-spousal caregivers (Kim, et al., 2013).

Several studies indicate older adults are more likely to seek bereavement

assistance from their primary care physician thereby making standardization of regular

screenings of bereaved caregivers by the provider feasible (Berman, et al., 2010, Cherlin,

et al., 2007). Seventy percent of bereaved caregivers did not use bereavement supports

post-death citing adequate support networks or no need for services (Cherlin, et al.,

2007). The same study also found transportation, lack of knowledge of services and

financial concerns as barriers to participation. Approximately fourteen percent of study

participants were unaware that bereavement supports were available, sixteen percent

lacked transportation to access services and five percent made the assumption that there

was a cost for services (Cherlin, et al., 2007). Ensuring health care providers are

knowledgeable of bereavement supports and make appropriate referrals is a key strategy

in meeting the needs of bereaved caregivers (Bergman, et al., 2011).

More research is indicated on effective models of intervention for caregiver

bereavement, identification of those in need of support and strategies to reduce barriers to

participation. This study attempted to address these gaps in the literature.

Conceptual Framework

A conceptual framework associated with this study was the strengths perspective, focusing on the older adult population. Strengths based approach or perspective to social work with this population recognizes the power to grow and change as one faces the challenges of aging. Self-determination, the want and need to be involved in one's own decision-making and choices about their care, is at the core of a strengths perspective. Central to a strengths perspective is the social worker's ability to focus on an older adult's abilities and strengths, rather than deficits, with the belief that this population has the capacity to change and grow, despite the challenges that may present because of aging (McInnis-Dittrich, 2014). The researcher included interview questions grounded in the strengths perspective conceptual framework.

Methods

Research Design

The purpose of this study was to gain a deeper understanding of the types of and need for on-going support services for caregivers after the loss of the caregiving role. This qualitative study relied on semi-structured interviews of staff of agencies that provide caregiver support services. The interviews allowed these staff to reflect on their experiences and share their perspective on the utilization of and need for on-going support to caregivers after the loss of the caregiving role. This study enhances the existing literature by assessing utilization of current services, identifying gaps in services and informing the expansion or enhancement of services for those in the post-caregiving role.

Sample

The study sample was comprised of staff from agencies providing caregiver support services funded by the Metropolitan Area Agency on Aging with the service area primarily being the seven county Twin Cities metropolitan area (three of the nine interviewed provide services beyond the metropolitan area). The researcher targeted professionals who managed caregiver support services or provided direct service to caregivers within one's agency. The scope of this study was with agencies serving older adults age 60 and over. Participants were recruited by phone or email from a list of agencies funded to provide caregiver support services by the Metropolitan Area Agency on Aging. (see Appendix A - Recruitment script). The sample size was nine participants.

Protection of Human Subjects

Several measures were taken to maintain confidentiality and protect the human subjects who participated in this study. Prior to completing the research, an application was submitted for approval to the Institutional Review Board (IRB) at St. Catherine University. The IRB reviewed and approved the research proposal to assure confidentiality and minimize risk to human subjects.

Once the IRB approved the proposal, the selection of participants and the data collection began. A consent form was given to potential participants (see Appendix B - Consent form). This consent form, created by the researcher, complied with the IRB requirements of St. Catherine University. The consent form included background information of the study, procedures, risks and benefits of participation, compensation, confidentiality, and voluntary nature of study, process for withdrawing and contact information for questions. Prior to participating in the interview the researcher and participant reviewed the consent form, addressed questions and assessed for understanding.   Participants were informed that his/her identity and remarks would be kept confidential. Recording and transcription data was stored on password-protected electronic devices and destroyed on May 31, 2016.   Participants were asked to sign the consent form as an indication of agreement to participate in this study.

Data Collection

Instrument. The researcher used a semi-structured interview to ask participants a standardized list of questions (see Appendix B - Interview questions). The questions were asked in a consistent order, yet allowed the researcher to ask probing or follow-up questions at her discretion. This flexibility permitted the researcher to ask clarifying

questions and to delve deeper into a participant's response. The fourteen questions,

developed by the researcher, were open ended and addressed the topics of assessing

needs of and providing on-going support to caregivers after the loss of the caregiving

role. Several questions were constructed with the lens of a strengths perspective in an

effort to identify how this conceptual framework may be promoted with caregiver and

bereavement support services.

       Process. To identify potential participants, the researcher gathered a list of

agencies providing caregiver support services in the seven county Twin Cities

metropolitan area.   The scope of this study was with agencies that serve older adults.

Using this list the researcher contacted each agency explaining the nature of the study and

requesting participation of a staff member who oversaw and/or provided direct services to

caregivers (see Appendix A - Recruitment script). At least three attempts were made to

contact and seek participation from each agency. If the respondent agreed to participate,

the researcher discussed the informed consent form and sent this electronically for his/her

signature (see Appendix B - Informed consent). A date for an in-person interview at the

participant's office was then established. Due to scheduling difficulties, two of the nine

interviews took place via phone. Several days prior to the interview, a reminder was

communicated via email or phone. At the beginning of the interview the researcher

reviewed the informed consent and reminded the participant that the interview was to be

audio-taped. The interview design was semi-structured and flexible. A benefit of the

semi-structured (also called nonscheduled-standardized interview) was that it allowed the

researcher discretion to probe deeper or order questions in a manner that best fit each

individual interview (Monette, Sullivan, DeJong & Tilton, 2014).

In an effort to maintain confidentiality of participants, each recording was identified with a number correlated to the participant. The recording of the interview was transcribed by the researcher and each transcription noted the identifier of the participant as the same number used on the recording. Recordings and transcription of interviews were stored on a password-protected electronic device and destroyed on May 31, 2016.

Data Analysis Plan

Coding and thematic development, the most commonly used analytic procedure in qualitative research, was used to analyze the data collected in the interviews (Padgett, 2008).   The audio-taped interviews were transcribed and the researcher read the transcription three times, highlighting concepts and then using these concepts to identify codes or repetitive patterns. After coding, the researcher reviewed the codes and identified the emerging themes. These themes that are relevant to the research question were analyzed and shared as findings of the study.

Findings

This study sought to better understand the formal support available to caregivers after the loss of the caregiving role. Interviews were conducted with professionals from nine of thirteen agencies providing caregiver support services funded by the Metropolitan Area Agency on Aging. Following the interviews, the recordings were transcribed and the data was analyzed. Two major categories presented - Caregivers and Support Services. Under the category of Caregivers, three themes emerged - identifying as a caregiver and transitioning out of that role, importance of addressing physical and mental health needs and focusing on the strengths of caregivers. The four themes presented within the Support Services category were value of planning for the future, linkage to and acceptance of support, time of transition, and urgency and innovation.

While the nine study participants had similar responses for the majority of the interview questions asked, they each shared differing viewpoints of how caregiver support services will look in the future. All agreed the changing demographics of the older adult population will increase the need for caregiver support services during and after the loss of the caregiving role. As one participant declared, "*we are not ready.*" The majority of participants agreed there is an immediate need to begin planning for the future of caregiver support services and these services must encompass needs of the caregiver during bereavement.

Sample

The sample was selected from a list of thirteen agencies that provide caregiver support services in the seven county Twin Cities Metropolitan area. Professionals representing nine of the thirteen agencies agreed to participate in the study. In addition to

providing services in the greater metropolitan area, three of these agencies provide services outside of this area, thereby serving a broader population.

Of the nine professionals represented in the sample, five had degrees in social work with one in nursing, counseling and music therapy respectively. One degree was unspecified. The range of experience in one's current position was from less than one year to over fifteen years with four of the nine having fifteen or more years of experience in one's current role. Seven of the nine have been serving older adults in a professional capacity for five or more years; three of whom have thirty or more years of experience. Hospice, long term care and senior services were the most frequently cited areas of areas of experience outside of caregiver support services. All of the participants were female and five self-identified as caregivers themselves.

Each of the agencies received Title III - E funding of the Older Americans Act from the Metropolitan Area Agency on Aging. This funding is designated for caregiver support services in one or more of four service categories. These include:

- Counseling - assisting caregivers in decision-making and problem solving via contact in person, phone or other technology

- Respite - providing temporary care or supervision to the care recipient in an effort to provide a break for informal caregivers, either in an in-home or group setting

- Access Assistance - connecting caregivers to available services and resources within their community

- Group Education - building capacity of caregivers to manage caregiving responsibilities and maintain one's own health and well-being (L. Smith, personal communication, April 1, 2016)

All nine agencies represented in the sample provided some level of service for each of the four categories listed above. In addition, each agency complied with or exceeded the annual evaluation requirements of the Title III - E funding. In fact, all of the agencies went to greater lengths to secure additional feedback on programs and services. This feedback was used to identify gaps and improve services for caregivers.

Caregivers

Identifying as a caregiver and transitioning out of that role. All nine study participants mentioned aspects of role identification as important to caregiving. Whether at the beginning of the caregiving experience or as one transitions out of the role following the care recipient's death, caregivers often struggle with identity issues.

When the caregiving role begins individuals often do not identify as caregivers, rather one believes it is their duty as a spouse, partner, adult child or chosen family member. Because individuals do not often consider themselves in an official caregiving capacity, one agency has conducted an awareness campaign ("You're a Caregiver") in an effort to educate others about the role of a caregiver and available support. The goal of helping caregivers identify their role as caregiver early on, rather than waiting until the need for services is imminent was referenced by one participant,

> *"That's the thing, people don't identify themselves as caregivers so then*
> *it's usually a crisis when we get a call. So when we hear people say, oh,*
> *my husband has just been diagnosed and someone referred them to us,*
> *what a blessing it is because we can start early with them and hopefully*
> *keep them out of crisis mode."*

Amongst certain minority populations caregiving is an expectation of being a part of a family. One participant that works with culturally specific older adult populations shared her view of the minority group with which she works most closely, *"For many it is something we do as families. Caring for one another it is how we roll. It's tradition."* Two participants reported culturally specific education campaigns as a way to reach minority groups that may view caregiving as a family responsibility and not seek available resources and support to assist them in their caregiving role.

According to all nine participants, most caregivers struggle to some degree with role identity following the death of the care recipient. Caregivers often question how to fill one's time, what one's new identity will be and how one navigates these changes. The length and difficulty of the struggle is often dependent upon the length of time one has been providing care. The longer the time spent caregiving, the greater the struggle. As one participant noted,

> *"If it's been 10 to 15 years that's a lifestyle change. They don't know*
>
> *what to do first. For so long the focus had been on the care recipient that*
>
> *the caregiver finds it challenging to focus on him/herself again."*

Several study participants agreed that finding purpose in life and what brings one joy may actually be part of the healing process. Four participants stated that encouraging activities outside of the caregiving relationship is helpful for role identification after the loss of the role. Carving out time for social connection with friends or other caregivers, or taking time to enjoy hobbies or recreational activities proved helpful.

The need to give back was noted by seven of the study's participants as connected to caregiver identity. Not only was it a way to acknowledge one's caregiving role, it also

allowed one cope to with and make meaning of the loss of role. As expressed by one

participant, *"She decided that one of the best ways for her to heal and move on was to*

help others do the same." Once the caregiver could make meaning of the loss, they were

better able to redefine one's identity.

Volunteering was identified as a way to give back after and make meaning of the

loss of the caregiving role. Each agency has volunteer opportunities, often pairing former

caregivers with current caregivers providing support in a mentorship capacity via phone

or in person. Opportunities to facilitate peer-led caregiver support groups are offered at

three organizations.

One participant questioned whether one ever really gives up their caregiving role,

"Just as we are all human beings, I can't help but think the caregiving role isn't

something you put on and take off. It is part of who you are." This aligns with the

philosophy of several participants who noticed that caregivers tend to continue in a

caregiver capacity to some degree, whether caring for an ill family member, one's

grandchildren or mentees in a volunteer experience. They agreed, once a caregiver,

always a caregiver.

Importance of addressing physical and mental health needs. Study

participants were asked to describe the need for attending to the caregiver's physical and

mental health needs. Each of the nine felt strongly about the need to connect early with

those in the caregiving role. Doing so allows the provider to establish a relationship and

offer services which may not be needed now, but most likely will be needed in the future.

The importance of this is illustrated in a remark by one participant, *"I've had one*

caregiver who passed away because they had not taken care of their own health needs. That is what we want to avoid."

Another participant summarized the sentiments of the participants about where the priority lies as a caregiver thinks of one's own needs, *"They definitely put their needs last. It's just so hard because they are consumed with what they are doing for their loved one."* Even though a caregiver might find a support group or respite beneficial, it becomes a low priority because it takes more effort than perceived worth.

When asked to identify the top physical and mental health issues of caregivers, the participants identified burnout as number one. Other issues identified by at least half of the participants included anxiety, depression, lack of self-care, chronic pain and physical health concerns such as arthritis, hypertension and diabetes.

The added burden of caring for someone with dementia was also noted by all nine participants. One participant acknowledged the strain related to ambiguous loss of those with dementia, noting the caregiver undergoes multiple, continual losses as the care recipient progresses through the various stages of dementia. She noted that physically the care recipient may be in good health, but cognitively they are impaired or absent. The participant's concern for the caregiver's mental and physical health was summarized by her remark, *"We know more often than not the caregiver gets sick before the person with the disease for whom they are caring."*

Focusing on the strengths of caregivers. One of the interview questions elicited responses on the strengths of caregivers while in the caregiving role that would prove beneficial following the loss of that role. While each participant identified a unique strength, one strength - a strong network of support - was noted by all nine. When asked

to identify who might be a part of this support network, participants most often identified family, friends, faith community, and support services staff or volunteers.

Other strengths noted by study participants included attitude, values, ability to be flexible, resiliency, sense of faith, strong/healthy relationship with the care recipient, and not getting caught up in the guilt. A participant expressed how one's attitude of *"recognizing at any given moment you are making the best possible decision with all of the knowledge and resources you have"* proves to be a healthy attitude for coping with all of the changes caregiving brings, during and after the loss of the role.

Support Services

Value of planning for the future. A common theme emerging from the data analysis was the value in caregivers planning for the future. A participant summarized the role of the professional in assisting caregivers in doing so,

> *"I help them get to the next level of service because that is a lot of what we do, connecting them to services and making sure that every step of the way they have the right resources and connections. It's helping them navigate the system."*

Another participant discussed the importance of timing of initiation of services, *"You really can't start too soon. It's coming. It can happen overnight or over the next 25 years."*

All study participants highlighted the importance and value of having a plan, both short and long term, and described the variety of services they offer related to planning. These include counseling services such as caregiver coaching and consultation, caregiver support groups and educational sessions. One participant noted greater importance of

planning if the caregiving situation involves two individuals in a relationship with one individual caring for the other without additional support from others. She pointed out the critical importance, in these situations, of discussing what happens if the caregiver becomes ill or dies first.

A benefit of planning for the future was the ability to set goals. The two participants who identified this stated that during coaching/consultation sessions a caregiver sets specific goals for oneself. Often these focus on retaining or redeveloping one's own identity. Both have observed those who do this seem to have less difficulty transitioning after the loss of the role.

Linkage to and acceptance of support. Participants explained one of the primary goals of caregiver support services was linking and providing caregivers with psychosocial support, that of professionals, peers and/or family. It is about establishing a relationship - a connection - so the caregiver understands they have support now, and in the future. This was summarized by one participant,

> *"I think successful caregiving that I have seen historically is when they*
>
> *have the support of positive people in their lives - whether it's kids, their*
>
> *own siblings, a great group of friends. When they have a positive network*
>
> *of support that echoes what we are saying. That for me is a sign we are*
>
> *going to go places, that this is going to work."*

Each of the nine participants emphasized the value of peer support. *"They are living it"* was the participant's most frequent response when describing why peer support was so valued. A participant shared her thoughts on the significance of peer relationships and support,

"The best cocktail we have found is when we have a professional

facilitator paired with a previous caregiver.   One of the things I have

learned is the best advice a caregiver can get is from another caregiver.

The best advice they are going to get is from someone who's either done it

or doing it. I'm not in their shoes."

This participant elaborated by saying that one of her most gratifying moments was to see

caregivers who attend support group together make connections outside of group. She

shared that caregivers may meet for coffee or attend an exercise class together, which

helps expand each caregiver's support network and enhances one's sense of self.

Volunteer and mentorship opportunities exist at each of the nine participant's

agencies. These include phone mentoring, providing respite, facilitating support groups

or speaking as part of a panel at educational forums and conferences.   Described as

mutually beneficial, participants report these volunteer opportunities provide

psychosocial support and a chance to redefine oneself, give back and heal.

A variety of responses were yielded when asked about acceptance of support

while actively caregiving or after the loss of the role. Two participants explained the

hesitation or resistance in asking for help with reference to one's pride, *"They may be*

resistant to ask for help. It's common. It's about pride." "It's hard to ask for help; it's

even harder to ask for specific help." The reluctance to ask for help may be due to

personal values or cultural background. One participant commented that this generation

of older adults has a great sense of pride in taking care of their own and may not be

comfortable reaching out for help.

Another consideration for older adults of non-majority race or ethnicity is the cultural customs and traditions. One participant highlighted the notion that even when younger generations have acculturated to western customs, their elders may threaten them because it is not part of their culture's custom to ask for help. She explained there is also a lot of fear - of being denied services or of not being treated fairly due to one's differences. This participant added what she saw as an effective strategy for reducing barriers to participation, *"I think it's important to have someone who looks like the community, serve the community."*

In addition to hesitation in seeking support, time and effort were also noted as barriers to participation in services, particularly with those identified as the sandwich generation. These individuals are caring for a parent or older family member as well as one's own children or younger family member. Coordinating respite or adult day services for the care recipient is often a struggle or hassle for the already overwhelmed caregiver. This was noted by three participants.

Geographic location was mentioned as an issue for caregivers seeking support. This was noted by two of the participants whose agency serves older adults outside the Twin Cities metropolitan area. In more rural areas there are fewer services available and greater distances to travel to access the services. Transportation to the available services was cited as a top concern for caregivers residing in outstate Minnesota. Identifying as a caregiver and lack of awareness of services were also named as barriers.

Acceptance of services is also affected by the belief of caregivers that services are not needed. Study participants shared that this perception was held both when caregivers were actively caregiving and after the loss of the role. One participant summarized her

belief that caregivers, while active in the role, are often living in denial and fear of what is happening with the care recipient's health. One participant shared her experience regarding the need for services when referencing a phone conversation with a newly bereaved caregiver,

> *"They say I'm no longer a caregiver or the person I've been caring for has passed away and that's just it. It's so matter of fact. We offer, how are you doing? Do you need any grief and loss resources? The majority of people say nope, I'm doing fine."*

All nine participants stated that finances are not typically a barrier to linking or accepting support. Each agency works with the caregiver and offers sliding fee scale or cost share if there are financial constraints. No one is turned away for inability to pay.

Time of transition. When asked what services are provided to caregivers following the loss of the caregiving role, over half of the study participants reported this being a gap in their continuum of services stating the primary reason was that funding is targeted for support services for those actively caregiving. Regardless of this, each of the nine participants was able to identify at least one intervention their agency provides to caregivers after the loss of the role. The participant responses centered around the theme that this period is a time of transition for the caregiver.

The most common response given regarding bereavement services during this time of transition was connecting with the caregiver to express condolences, offering emotional support and referring to grief and loss resources in the community. One participant summarized the need for continued connection, *"The caregiver appreciates*

the support and psychological contact so they are not in a hurry to severe ties and have

us say it's time to get your life back."

When asked if there is a time limit on how long bereavement services are

available to the caregiver, the range of responses was from one time to quarterly contact

to as often as needed. Each specified the timeframe was dependent upon the caregiver's

individual circumstances. The length of time the services are offered is typically

unwritten. If a caregiver calls, the provider will at the very least lend a listening ear and

refer to outside resources as needed. Two participants highlighted this transition period

from active to bereaved caregiver. One stated, *"We try to allow space and opportunity*

for them to come back and be a part of whatever they choose," with the other participant

declaring, *"There absolutely is a transition period, "We would be horrible human beings*

if we went cold turkey on them."

Providing emotional support to caregivers following the loss is standard practice

for each of the nine agencies involved in this study. One agency hosts a bi-annual

remembrance event which caregivers may attend on a voluntary basis. This offers the

bereaved a chance to publicly honor and remember their care recipient. For many

caregivers there is a sense of relief from the physical and emotional burden of caregiving.

With this often comes a feeling of guilt. Continued consultation, support group

participation or referral to individual counseling help address these conflicting feelings of

grief, relief and guilt during this time of transition.

At most agencies, bereaved caregivers were allowed to continue to attend

caregiver support groups, even though the support group is designed for those active in

the caregiving role. One participant described the need that is fulfilled with continued attendance at the support group, *"I think that sense of community is helpful for people."* Participants also commented that support groups offer opportunities for former caregivers to give back by sharing their experience via co-facilitation or mentorship opportunities. This allows for continued connection while recognizing they are in a different place with their caregiving experience.

One participant shared her agency is developing a new support group as a pilot program. With a focus on bereavement support, this support group will be time specific and very structured with a focus on bereavement. The goal will be to help caregiver transform from their caregiving experience to life after caregiving.

Another need identified following the loss of the role is financial management assistance, with common requests for programs that teach skills such as balancing one's checkbook or assistance selling one's home. Participants report their role with meeting the financial assistance needs of caregivers is referrals to other agencies that offer financial management or credit counseling.

Several participants mentioned that oftentimes caregivers are well-equipped to move on, or transition, partly because of the resources they have been connected with during the caregiving role. Much of the focus in support group and with caregiver consultation is on the loss of identity that may occur in the caregiving role. Preparing caregivers for this loss and building support systems beyond the staff of the caregiver support agency were identified as the primary goals by study participants. The importance of accessing services while active in the caregiving role is highlighted by one

participant's remark, *"Utilizing services before the loss of the role helps significantly after the loss of the role."*

The needs of caregivers vary greatly following the loss of the caregiving role. Two of the participant's responses summarize this range of need. The first participant expressed, *"Some are ready to fly on their own; others need support, skills or resources."* Another participant shared,

> *"There is an unmet need because of how people define themselves. When the person dies they no longer think they are a caregiver. There is kind of an assumption that they don't need the service yet this is often when support is so critical."*

Urgency and innovation. A final theme emerged as participants gave responses to the question of what caregiver support services will look like 25 years from now. Each participant stressed innovation as an underlying thread and recognized the urgent need to beginning planning now in order to be prepared for the increased need of the future. One participant shared her thoughts about this, *"As society ages there are going to be a lot more older adults who need support at home so I think caregiving is going to be a normal way of life for people."*

Another participant responded to the growing need with, *"We are not prepared."* This participant believes that the stigma of asking for help by the baby boom generation has been reduced; therefore this cohort will be more receptive to counseling, coaching and other support services. She stated, *"The current older generation loathes asking for help. Baby boomers are more comfortable doing this and have an expectation that the government will bail them out."*

While discussing the increased need another participant concurred with the former participant's statement by declaring, *"It's all hands on deck right now."*

Two other participants indicated the increase in minority older adult population will lead to the need for more innovative, culturally specific services. A participant working specifically with minority populations referenced greater health equity with statistics indicating that the minority population is going to be the main population. With this comes the demand for more professional graduates that can work in the field of gerontology with minority populations.

Several participants anticipate significant macro-level changes in policy and shifts in funding to support a continuum of services for caregiver during and following the caregiving role. One of the participants asserted that funders currently do not see the need for support services following the loss of the caregiving role. *"They are just so focused on the active caregiving role that they don't realize it's a huge thing when a caregiver loses that role and still needs our support."*

Another participant expressed the need for changes to the Family Medical Leave Act to ensure the economic security of those working and being supported at work while they are in the caregiving role. Maintaining a healthy work/life balance will be crucial to the working caregiver's well-being.

Several participants forecasted novel changes at the community level, including the need for specialized housing communities as well as coordination of services that will allow one to age in place rather than transition to facilities providing higher levels of care. A concern was expressed by one participant who questioned whether the increased number of assisted living facilities is truly meeting the future need,

"What are we going to do with all the assisted livings? We are making

extreme measures to build housing for them instead of investing that

money to make the housing they are in more accessible."

Another participant had similar sentiments when discussing state-of-the-art

housing options, noting that European countries are developing innovative communities

offering housing, stores, healthcare services and recreational/entertainment options all on

one campus. These communities are staffed by trained professionals who specialize in

dementia care, *"It would be cool if that is the trend rather than more nursing homes."*

Several participants predict new and increased community based programs

offering natural connections to services where one works, lives or attends faith services.

One participant gave an example of community based programming that is currently

showing great promise in increasing awareness of Alzheimer's Disease and engaging

multiple sectors of the community to become more dementia-friendly. She verbalized

how this increased connection at the community level would allow an individual to go

anywhere in the community and feel safe and supported.

A final mezzo-level recommendation was referenced by one participant,

"In my perfect universe what I'd like to see is at the point of diagnosis the

physicians are referring them to us so we can talk with them right away

about what we can do to help."

This participant emphasized that information needs to be communicated to the right

people at the right time. Often it takes a caregiver several years to initiate a call for

assistance and she would like to see them make the connection sooner. Another

participant's response of providing a continuum of services that is more seamless than it is currently aligns with the previous respondent's opinion.

The majority of participants identified the top priority for caregivers will continue to be the need for connection. Exploring new ways for personal connection and relationship development will remain a constant in the future. The importance of this is illustrated by one participant's remarks, *"Even one conversation can make a difference for somebody. It can change your outlook on your role and situation and can bring you from the dark to the light."*

Making connection with a caregiver early in one's journey provides the caregiver with a single point of contact to assist with current and/or future needs. All nine participants recognize each caregiver's needs are unique and an individualized approach with a continuum of services will likely be a model of the future, just as it is today. One participant described the one size fits all approach as not serving the caregiver's best interests.

Two participants articulated the continued need for grief and loss support and funneling caregivers to appropriate services following the loss of the caregiving role. All nine participants identified the lack of services for caregivers after the loss of the caregiving role as a huge gap and an area that needs considerable attention. One participant expressed this need by stating, *"I don't sense that a lot of people are providing any formal services after someone is out of their caregiving role."*

Finally, one participant expressed difficulty in answering the question of how caregiver support services might look in 25 years, stating *"they will look very different."* Other participants predicted some of these differences will center around the method for

delivering services recognizing that advances in technology will offer new and more

effective options for reaching caregivers, particularly those who are working or residing

in rural areas.

Discussion

It is well documented in the literature that caregivers often neglect their own physical and mental health needs while caring for another, which in turn may lead to serious health consequences while active in the caregiving role (Toseland, 1990). Less is known about the health status of caregivers following the loss of the caregiving role. The limited data available indicates one-third of caregivers seek support of mental health professionals in bereavement (Brazil, Bedard & Willison, 2002). While long-term caregivers often feel a sense of relief from the burden of caregiving following the loss of the role, they also experience grief, physical health issues and financial concerns.

Caregiver burden is the focus of much of the literature on this topic, however, studies also document the gains a caregiver experiences. Caregivers often find satisfaction and gratification with their role. The role of caregiver gives one a sense of purpose, fulfillment and personal growth (Sanders, 2005). Certain personal characteristics often predict which caregivers will experience gains, and may be considered strengths when adapting to the loss of the care recipient.

This discussion compares the findings of the present study with the findings of the literature review on caregiver demographics, burden and gain, support groups, loss of role, grief and loss, financial concerns, health status and bereavement supports. Implications for social work practice, policy and research are presented. The comparison of study findings with past literature offers conclusions that may prove advantageous in future work with caregivers during and following the loss of the caregiving role. The strengths and limitations of this study are shared at the end of this discussion.

Caregivers

Identifying as a caregiver and transitioning out of that role. The definition of a caregiver is neither clear nor consistent in the literature. A generally accepted definition of caregiver is anyone who has a significant personal relationship with and provides assistance for someone with a life-threatening or chronic condition (Blum & Sherman, 2010, Hudson, et al., 2012). The findings of this study indicate that individuals do not often identify as a caregiver, rather it is something one just does due to cultural upbringing and customs. This leads to a recommendation for more education and awareness about what a caregiver is and isn't. A broad based definition that encompasses biological and chosen family, friend, neighbor or other individual with a significant relationship is warranted. Clarity of definition may lead to more frequent and earlier access of support services, which participants stated is an important factor in better outcomes for the caregiving experience.

Importance of addressing physical and mental health needs. Both the present study and the literature review highlight the importance of addressing the physical and mental health needs of caregivers. Taking care of one's own health needs while in a caregiving role may lead to better health outcomes during bereavement. The study's participants stressed the importance of connecting caregivers to resources early for planning and linkage to services. Services such as in-home or group respite or adult day programs provide an opportunity for the caregiver to have a break and care for their own health and well-being. Oftentimes the caregiver neglects one's own health because of the time and effort it takes to arrange for respite care. The care recipient may also be reluctant or become anxious or angry if the caregiver leaves, which may lead the

caregiver to feel it is more of a hassle than helpful. The present study's participants

validated the literature by Brazil (2002) that caregivers who reported poor physical health

while in the caregiving role are more likely to report mental health issues during

bereavement. Caregiver support services, such as those provided by the study's

participants, are designed specifically to maintain or improve the physical and mental

health status of caregivers.   Study participants agree that caregivers stress level and

health is better when available services are utilized.

Focusing on the strengths of caregivers. Consistent with what is reported in

previous research, the present study underscored the value of tapping into the strengths of

caregivers that may reduce the stress and burden associated with the caregiving role.

Koener, et al., (2009) identified two interpersonal factors - social support and quality of

pre-caregiving relationship between caregiver and care recipient - as linked to a caregiver

viewing one's caregiving role in more positive light. This study's participants were in

agreement that caregivers with a strong network of support had a more positive outlook

on the caregiving situation and were better able to navigate the highs and lows associated

with the role. Those supporting the caregiver offered an outlet for one to express

feelings and escape from the burden associated with providing round the clock

supervision or care. In addition, several participants discussed the health of a

caregiver/care recipient relationship prior to the caregiving situation as an asset. Those

with a strong, healthy relationship seemed to fare better.

This study also found other attributes that served as strengths to a caregiver in

navigating the difficulties of one's role. These centered on positive attributes of

personality and spirituality. Although there is a need for additional research in the area of

caregiver gains or strengths, the existing data supports the idea of certain personality

characteristics in benefiting one in a caregiver capacity.

Support Services

      Value of planning for the future. A theme that emerged in the present study

was the value of the caregiver developing a plan for the future that includes short and

long term goals. Through support services such as consultation, coaching or support

groups, caregivers receive emotional support, education and assistance with goal setting.

These services aim to reduce caregiver burden and burnout while increasing a caregiver's

support network.

      Financial concerns of caregivers were specifically mentioned by study

participants and surfaced in the literature review as well. Uncertainty around one's

financial future weighs heavily on a caregiver's mind. Studies indicate as high as 45% of

caregivers express financial concerns during bereavement (Holtslander & Duggleby,

2010). Several participants discussed their role in connecting caregivers to financial

planners and other professionals who can assist the caregiver with current and future

financial concerns.

      Participants of the study emphasized the critical nature of connection and

communication with peers and at least one professional. A review of the literature

related to what is effective in helping caregivers prepare for the loss of one's role reveals

similar findings, although limited studies have been conducted on this subject. One study

determined that communication around end-of-life, in an effort to reduce uncertainty, is

of primary importance in helping caregivers prepare for bereavement (Hebert, et al.,

2009). Another study also indicated advanced knowledge in being able to anticipate and

prepare for the many transitions that present in caregiving situations (Blum & Sherman, 2010).

The alignment of existing research with the results of the present study validates the importance of talking with caregivers about plans for one's care recipient and also for oneself. An opportunity for this exists when health care or social service providers discuss advance care directives with caregivers and his/her care recipient. With the institution of reimbursement by Medicare for these physician-patient discussions there may be a positive shift towards more communication and planning that will ultimately benefit the caregiver during and following the caregiving role.

Linkage to and acceptance of support. One of the primary goals of caregiver support services is providing psychosocial support during and after the loss of the caregiving role. The range of emotions experienced by one in a caregiving role is vast. Grief, guilt, sadness, anger, relief and pride are just a few of the common emotions experienced by caregivers and mentioned by study participants during their interviews.

Caregiver support groups were offered by all nine agencies represented in the study. The participants share the opinion that previous studies have demonstrated regarding the efficacy of caregiver support groups providing psychosocial support by increasing a caregiver's network of support and utilization of coping skills while reducing subjective burden. The literature supports the notion that peer and professional led support groups yield similar outcomes. Study participants would concur with this finding stating that caregivers often find peer support more helpful because they have a shared experience.

Addressing the psychosocial needs of caregivers, current and past, is fundamental to the physical and mental health of those caring for another. The long term impact (described in the literature as one year after the loss of the caregiving role) of caregiver support groups has yet to be demonstrated. Additional research in this area is warranted.

 Barriers to participation in caregiver and bereavement support can be extrapolated from research about specific interventions and specific demographic populations. Often cited in literature is reluctance to ask for help due to pride and/or cultural factors. This finding is supported by participant responses in the present study. The hesitancy to utilize services is seen within the active and bereaved caregiver population.

Certain demographic populations are also reluctant to access services, for fear of being denied services or treated unfairly. This was noted by the study participants with several minority racial groups. In the literature it has been documented within the LGBT community.

Geographic location was identified as a potential barrier for caregivers linking to and accepting support by both study participants and in the literature. Those living in rural areas are often underserved due to lack of available services and/or transportation. Virtual services, such as online support groups, are becoming more popular and show promise particularly with those caregivers who are employed or living where access to services is limited. Study participants recognized the current older adult population who are less technology savvy will be joined by those coined as digital natives. Exploring more integrated technology and other new methodologies to deliver services may reduce

the barriers to participation in caregivers both linking to and accepting support at a

critical time of transition in one's life.

      Time of transition. A gap exists in the literature on support services for

caregivers during the time of transition from active caregiving to bereavement after the

loss of the role. The focal point of most of the literature is on caregiver support services

while one is active in the caregiving role. The available research relates to grief and loss

and access to mental health support during bereavement. Studies indicate that

professional help is accessed in about one in three bereavements (Brazil, et al., 2002).

The primary reasons for referral are symptoms related to unresolved or complicated grief

(Bergman, et al., 2010).

      This study also found that there is a gap in formal support services for caregivers

following the loss of the caregiving role. While each participant was able to identify one

or more services offered during this time of transition, the majority agreed there is a gap

in continuity of care for the bereaved caregiver. The most common intervention offered

was providing emotional support and linkage to grief and loss resources.

      Continued participation in caregiver support groups was an area of conflict for

several of the study's participants. While many caregivers continued to attend their

caregiver support group following the loss of the role, participants expressed

apprehension about this, questioning if this is in the best interests of group members and

group dynamics. The participants stressed the need for and value of continued

connection, yet recognized that active and bereaved caregivers are often at different

places on the caregiving journey.

In response to this, one participant's organization has developed a support group for bereaved caregivers. Yet in its pilot stage, it is expected to meet the specific needs of the bereaved caregiver during this time of transition by providing emotional support, connection to resources and opportunities for exploration of one's changing identity.

Not all caregivers have the need to access services following the loss of the caregiving role. Participants of the present study suggest that the needs vary by individual caregiver stating many are well-equipped to transition to life after caregiving. It is important for practitioners to keep in mind a one size fits all approach is not likely to be effective or cost-efficient. Assessing the bereaved caregiver's needs will guide the practitioner in recommending support services best tailored to the individual needs of each caregiver.

Urgency and innovation. The final theme which emerged from the present study was recommendations for future caregiver support services. The data provided by the study's participants fills a gap in the literature as limited research has been done regarding the future of caregiver support services during and after the loss of the caregiving role. The range of participant responses indicate varying viewpoints about what the future will bring for these types of services, however, the need for connection and support remains constant.

Participants expressed a sense of urgency for addressing the future systems of support for the caregiving population, including review of policies and programs at all levels (micro, mezzo and macro). Macro-level recommendations centered on legislation to enhance caregiver support services by providing greater access and a broader range of services that include the bereaved caregiver. Increasing support for the working

caregiver through workplace friendly policies that include family medical leave for

caregivers, flexible work schedules and access to support services at the workplace were

proposed by several study participants.

      Innovative community based programs and services were also recommended by

several participants. The goal of these would be to support the caregiver while allowing

the care recipient to age in place. One participant suggested investigating models of

community support used in other countries that focus on specialized caregiver and care

recipient-friendly communities within a larger community.

      Another systems-level approach is to initiate care earlier by coordinating a

referral system with all levels of health care providers. Designing systems for immediate

referral by one's health care provider to caregiver support services is believed to greatly

benefit both the care recipient and the caregiver. As several study participants mentioned

access to caregiver support often happens too late or not at all.

      More programs and services aimed at meeting the needs of minority populations,

including those of color and identifying as LGBT, were cited as a necessity by several of

the study's participants. Finally, participants recognize the need for and envision greater

grief and loss support for caregivers, to help them *"grieve the losses on top of losses"*

that accompany the caregiving role - while active in the caregiving role and following the

loss of that role.

Implications for Social Work Practice

      The results of this qualitative research study, along with the information obtained

in the literature review, demonstrate the value of support services during the caregiving

role. The study's participants, who were caregiver support services professionals, also

affirmed the need for and gaps in providing services following the loss of the caregiving role. While all participants' organizations provided some type of support after the loss of role, very few had formal protocols or services in place. This serves as an opportunity for these professionals - primarily social workers - to initiate dialogue within their agency about micro, mezzo and macro level changes to expand their scope of services beyond the active caregiving role.

 Much of the need following the loss of the caregiving role centers around grief and loss. Familiarizing oneself with current theories of grief and loss and best practices related therapeutic interventions is an essential for social workers and other professionals in the field. Doing so ensures that social workers meet one of the Council on Social Work Education's core competencies of social work practice which is to engage in research-informed practice and practice-informed research (Council on Social Work Education, 2016).

Reducing barriers to participation through development and initiation of culturally specific programs and services will be an important role of social workers. Awareness of and response to the unique needs of special populations is a responsibility of professionals in the field. Working collaboratively to develop creative ways to reach isolated populations will help safeguard those in more rural areas from the negative toll caregiving can take on one's mental and physical health.

Social workers are in an excellent position to give voice to the needs of caregivers. Because social workers work so closely with caregivers they have a unique understanding of the depth and breadth of caregiver strengths, burdens and needs. Social workers develop a close professional relationship with clients, connecting them with

valuable resources and services, to enhance the caregiver's quality of life, and in turn the care receiver's life as well. Providing culturally sensitive services which incorporate best practices in a caring, compassionate way is the ultimate implication for social work practice.

Implications for Policy

The Older Americans Act currently is the primary source of funding dedicated to caregiver support services. Through Title III-E it is mandated that these funds be used only for programs and services for caregivers who are actively providing care. Upon loss of the caregiving role eligibility for services ceases, unless the service agency has additional funding streams to support continued programming. The nine professionals interviewed for this study indicated that each of their respective agencies continues to provide services to caregivers following the care receiver's death using funding sources other than Title III-E to cover the costs of continued service.

The Older Americans Act is awaiting reauthorization at the federal level[1]. Advocates for older adult services are lobbying Congress to reauthorize these funds which flow through to local Area Agencies on Aging for disbursement. If Congress does not reauthorize the Act, caregiver support services will be dramatically reduced or eliminated. Advocacy of federal legislation impacting the lives of older adults is a top priority of several professional organizations and coalitions including the National Association of Social Workers, The Family Caregiver Alliance and AARP. Locally, many organizations like LeadingAge Minnesota and the Metropolitan Caregiver Service

1The study was conducted and completed prior to the reauthorization of the Older Americans Act in the spring of 2016

Collaborative (MCSC) work diligently to promote effective policies and practices on behalf of older adults and caregivers. Eight of the study's nine participants regularly attend the MCSC meetings finding the networking and resources to be a valuable use of one's time.

There are also opportunities for social workers to advocate for mezzo- and macro-level changes. Within one's organization (mezzo-level), reviewing and promoting more caregiver-friendly policies and practices, whether for clients or employees, is within the scope of social work practice. The end result is serving clients in ways that best align with social justice principles of social work. At the macro-level, social workers can provide education on caregiver's needs, during and after the loss of the role, and advocate on behalf of this population for legislation and policies that promote maintenance or improvement of one's health status. Advocating for or leading research on caregiver and bereavement support services is yet another imperative role of social workers.

Not only is awareness of and advocacy for enhanced caregiver support services a topic of interest to practitioners, it is also on the minds and hearts of current and former caregivers. Through grassroots efforts such as ACT on Alzheimer's, caregivers, community members and professionals come together in an effort to educate and engage all sectors of the community on priority aging issues. As highlighted by one study participant, there is an interest on the part of former caregivers of an ACT community in broadening caregiver support to include services after the loss of the caregiving role. The efforts of these grassroots, community-based coalitions may prove beneficial in enhancing the level of support for all caregivers whether one is currently active in the caregiving role or not.

Point of entry is another policy consideration for caregiver support services. Too often caregivers access services when in crisis, rather than earlier when plans can be made to avert potential crises. When asked of suggestions for enhancing caregiver support services, one participant emphasized the need for better coordination with healthcare providers for immediate referral to support services following a dementia diagnosis. Earlier point of entry may be considered a policy issue at both the organizational or statutory level. A health care system may opt to implement a comprehensive continuum of caregiver support from diagnosis to bereavement, and it might be considered as a mandate through Medicare.

The study participants expressed the need for continued enhancement and growth of services to meet the increased needs of caregivers while actively caregiving and after the loss of that role. Developing specific policies, programs and services to meet the needs of caregivers in bereavement is gaining attention of professionals and policy-makers and is likely to be a top priority at the local, state and federal level in the near future.

Implications for Research

There is a dearth of empirical data on the needs of caregivers following the loss of the caregiving role. Further investigation of these needs is critical in identifying effective interventions and services that will support the caregiver as one makes this transition in role. Research comparing the health status of caregivers utilizing caregiver support services while actively caregiving with those who do not access services is also indicated. This will help inform social work practice with caregivers who are actively caregiving and those who are no longer doing so. Supplementary research is needed to better

understand barriers to and benefits of utilization of caregiver support services and whether an individualized or one size fits all approach is preferable.

This study sought feedback from professionals working within caregiver support service agencies. The study's participants gave feedback from the lens of professionals serving caregivers rather than care recipients. Research with professionals such as respite or hospice care providers whose primary focus is on the care recipient may provide a unique perspective and valuable insight. Future studies are also indicated with other populations such as caregivers themselves. Several participants in this study noted the interest of former caregivers in participating in research to enhance the knowledge base on this topic. Studying former caregivers offers a novel perspective of the need for and efficacy of caregiver support programs following the loss of the role. The caregiver has lived the experience and has the greatest understanding of need.

Qualitative and quantitative research of the caregiver perspective would greatly benefit practitioners and policymakers alike. Investing funds to support research of evidence-based practices that maintains or improves the health of caregivers, while actively caregiving and after the loss of the role, has the potential for significant health care cost savings for our nation. Given the change in demographics predicted in the near future, it would behoove aging services leaders and policymakers to support continued research.

Strengths and Limitations

A strength of this study was the use of the interview as a means of data collection. This semi-structured interview design allowed the researcher discretion in varying the order of the questions in response to the participant's answers. It also allowed the

researcher to probe deeper and spontaneously ask additional, relevant questions based on the participant's responses.

A limitation of this study was the small sample size which did not allow one to generalize the results to the larger population. This study sample was limited to professionals from agencies that primarily provided caregiver support services within the seven-county metropolitan area of Minneapolis/St Paul. In addition, the researcher limited the sample to professionals rather than including caregivers themselves. Understanding the perspective of caregivers would potentially add significant value to the limited body of research on the needs of caregivers following the loss of the caregiving role. A final limitation was the reliability of coding due to the use of a single researcher. A partner-reliability check was not used as part of this study, therefore decreasing accuracy of coding and increasing researcher bias.

Conclusion

The demographics of the older adult population are shifting with more Americans living longer due to advances in medical care. With this comes the increased need for older adult services, including those who are in a providing care to another in an informal caregiving situation. This study set out to explore the availability of and need for on-going support for caregivers after the loss of the caregiving role.

The findings of this study add valuable insight to the needs of caregivers both during and after the loss of the caregiving role. The need for connection and support continues for caregivers regardless of where one is in the caregiving journey. Caregivers who access support services while in the caregiving role may have better physical and mental health outcomes following the loss of the role. In the very least they are better prepared for the transition. These findings appear to be consistent with those in previous caregiver studies.

Planning now for the future is imperative, not only for caregivers, but also for our nation. Policy and program enhancements that support caregivers are an immediate need at the local, state and federal level. Social workers, caregiver support specialists and other geriatric professionals have the opportunity to take the lead with initiating changes to policy and practice that will benefit the caregiver during and following the caregiving role.

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Appendix A

Recruitment Script

Date:

Dear _____:

      Greetings! My name is Judy Johnson and I am a graduate student at the University of St. Thomas/St. Catherine University. I received your contact information from Leanna Smith, Grants and Contracts Manager/Program Developer at the Metropolitan Area Agency on Aging. I am seeking participants for a research study.

      My study will investigate the on-going support for caregivers after the loss of the caregiving role. I would like to interview professionals who manage or supervise caregiver support programs, or those who provide direct services to caregivers. In-person interviews are preferred; however, video technology may be used to accommodate schedules and those who work a significant distance from the Twin Cities metropolitan area. The interviews will be scheduled at the time and location of your choosing. Interviews are designed to take 60 - 75 minutes and will be audio-recorded. The interview process will occur in the months of January and February 2016.

      Your identity will be kept confidential throughout the study. Participation is voluntary and you may withdraw your information at any time. Your current or future relationship with the University of St Thomas/St Catherine University will not be affected by your participation in this study. There are no direct benefits to participating in this study. Compensation will not be provided to participants.

      If you are interested in participating in this study or if you have questions, please feel free to contact me at XXX-XXX-XXXX or XXXXXXXX@stthomas.edu. I look forward to speaking with you soon.

Sincerely,

Judith Johnson, B.S.
Clinical Master of Social Worker Student
University of St Thomas/St Catherine University

Appendix B

Consent Form

SUPPORT FOR CAREGIVERS
AFTER THE LOSS OF THE CAREGIVING ROLE
INFORMATION AND CONSENT FORM

Introduction:
You are invited to participate in a research study investigating on-going support for caregivers after the loss of the caregiving role. This study is being conducted by Judith Johnson, a graduate student at The University of St. Thomas/St. Catherine University under the supervision of Dr. Rajean Moone, a faculty member in the Department of Social Work. You were selected as a possible participant in this research because you are an identified professional working in the field of caregiver support services. Please read this form and ask questions before you agree to be in the study.

Background Information:
The purpose of this study is to explore the types of on-going support available to caregivers after the loss of the caregiving role. Ten professionals working in the field of caregiver support services are expected to participate in this research.

Procedure:
If you decide to participate, you will be asked to complete a semi-structured interview answering 14 questions. It is anticipated the interview will be approximately 60 - 75 minutes in length.

Risks and Benefits of being in the study:
There are minimal risks for respondents who participate in this survey.
There are no direct benefits to you for participating in this research.

Confidentiality:
Any information obtained in connection with this research study that can be identified with you will be disclosed only with your permission; your results will be kept confidential. In any written reports or publications, no one will be identified or identifiable and only group data will be presented.
The interview will be audio-taped. I will keep the audio-recording in a password protected electronic device. The interview will be transcribed. The transcription will be kept on a password protected computer and any paper copies of the research results will be stored in a locked file cabinet in my home office. Only my advisor and I will have access to the records while I work on this research project. I will destroy all original audio-recordings, electronic files and written reports that can be linked back to you no later than May 31, 2016.

Voluntary nature of the study:

Participation in this research study is voluntary. Your decision whether or not to participate will not affect your future relations with the University of St. Thomas or St. Catherine University in any way. If you decide to participate, you are free to stop or withdraw at any time without affecting these relationships.

New Information:

If during course of this research study I learn about new findings that might influence your willingness to continue participating in the study, I will inform you of these findings.

Contacts and questions:

If you have any questions, please feel free to contact me, Judith Johnson, at 612-562-7904. You may ask questions now, or if you have any additional questions later, the faculty advisor, Dr. Rajean Moone, 651-235-0346, will be happy to answer them. If you have other questions or concerns regarding the study and would like to talk to someone other than the researcher(s), you may also contact Dr. John Schmitt, Chair of the St. Catherine University Institutional Review Board, at (651) 690-7739 or jsschmitt@stkate.edu.

You may keep a copy of this form for your records.

Statement of Consent:

You are making a decision whether or not to participate. Your signature indicates that you have read this information and your questions have been answered. Even after signing this form, please know that you may withdraw from the study.

I consent to participate in the study.

_____

Signature of Participant   Date

_____

Signature of Researcher   Date

Appendix C

Interview Questions

1. Please tell me about your professional background and your position with this agency. What motivated you to get involved in this field?

2. Does your program target care recipients, caregivers or both? What type of services does your program provide to caregivers?

3. What geographic area, specific populations or communities and/or age ranges does your program serve?

4. Will you describe the health or mental health of the care recipients of the caregivers in your program? How about the caregivers?

5. What type of on-going support is offered to caregivers following the loss of the caregiver?

6. For what length of time are these services available to caregivers?

7. What are the qualifications/credentials of staff providing these services?

8. What percentage of your caregivers participate in these on-going services?   In your experience, what are the barriers to participation?

9. Please describe an example of a caregiver that you worked with that transitioned well after the loss? What factors contributed to it being a positive transition (personal and/or program related)?

10. How do you know your program is working? Are you using any kind of evaluative tool? Please share a success story.

11. Describe the strengths of caregivers, in general, that will be helpful after the loss of the caregiving role. What do you feel are the most significant needs of caregivers following this loss?

12. If resources were no object, how might your services be enhanced?

13. Describe any work that you do with the broader caregiver provider network.

14. If you are a news reporter in 2040 doing a story on caregiver services, what will be featured in your story? How will caregiver support services be the same or different 25 years from now?