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Identifying and Mitigating Caregiver Burnout: The Role of Adult Day Social Workers

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Identifying and Mitigating Caregiver Burnout: The Role of Adult Day Social
Workers

by

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MSW Clinical Research Paper

Presented to the Faculty of the
School of Social Work
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St. Paul, Minnesota
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Master of Social Work

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

Abstract

This qualitative research study will explore the role of adult day social workers in identifying and mitigating caregiver burnout. To collect data for this study, eight semi-structured interviews with adult day social workers were completed to analyze their experience with caregivers, their role in recognizing burnout and their response to caregivers experiencing burnout. A grounded theory methodology approach will be used to analyze data. This method will use an open-coding process that will lead to selective coding, which will assist in identifying and validating themes and concepts from the participant's responses to interview questions. The findings from this study indicate the strong role adult day social workers play in identifying burnout among caregivers by providing support that aligns with best practices in the adult day setting. Further research in this area will also assist social workers in the continuation of best practice development and to be effective in providing the needed support of caregivers on a mental, psychological, physical and emotional levels.

Keywords: caregiver, caregiver burden, caregiver burnout, adult day services, dementia, older adults

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It is estimated that by 2060 the number of persons 65 years or older in the U.S. will reach 98 million (Administration for Community Living, 2016). With age, the chances of developing a form of dementia increase. Dementia is a general term for memory loss and other intellectual abilities serious enough to interfere with daily life. Added difficulty of performing daily tasks or activities of daily living (ADLs) is known to accompany the progression of dementia, which may require an older adult to need additional assistance from a family member or informal caregiver in the community. These daily tasks may include but are not limited to bathing, dressing, walking, eating or preparing food, and accomplishing household tasks or finances. In 2013, it was estimated that 30% of individuals 65 years or older receiving Medicare benefits in the community had trouble performing at least one ADL independently (ACL, 2016). The Alzheimer's Association (2016) estimates that the population of persons 65 years or older with Alzheimer's has the potential to reach 13.8 million by 2050. It is estimated that of the 70% of adults living at home, approximately two-thirds of them are living with a family caregiver (Gould & Basta, 2013).

Caregiving is a normal and equally shared part of most dyadic relationships (Faurth et al, 2012). Significant changes in these relationships and roles occur when one person in a family or relationship develops a disease like dementia that progresses over time and disables that person from performing their own daily activities of life, therefore prompting caregiving (Fauth et al, 2012). Decades of research have indicated that caregiving for an individual with dementia can be an ever changing and challenging process (Yeager, Hyer, Hobbs & Coyne, 2010). 61.6 million familial caregivers provided some type of unpaid care estimated at nearly \$450 billion in 2009

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(Robinson, Buckwater & Reed, 2013). Within community systems of support, these caregivers are “often forgotten clients in need of help”, especially since the focus of support systems are aimed at keeping individuals in their communities longer causing the caregiver burden to grow (Cheung & Ngan, 2007).

Caregiver burden is defined as a complex reaction to taking care of someone who is ill that may include varying levels of perceived stress (Kim, Chang, Rose, & Kim, 2011). It is known that caregivers are most often women, spouses, adult children or in-laws. Familial/informal caregivers may experience psychological and/or physical impacts on their wellbeing as a result of caregiving for a person living with dementia. Depression, as well as concerns about quality of life and difficulty managing or adapting coping strategies, is common amongst caregivers (Kim, Chang, Rose, & Kim, 2011). Additionally, dementia caregivers in comparison to non-dementia caregivers, assist with more ADL's, spend more hours on care and confront more behavioral issues from their loved ones (Hurley, Patterson & Cooley, 2014). It is not unusual for caregivers to need respite along with training, education and other interventions due to burden or burnout being experienced in a variety of ways (Noelker & Browdie, 2012).

Respite care is defined as a short-term intended relief from caregiving duties that frequently has a goal of delaying assisted living or skilled nursing facility placement (Gottlieb & Johnson, 2000). Respite services differ in length of time, from a couple of hours to a week or two. Professionals have identified respite as a crucial support for caregivers (Gottlieb & Johnson, 2000). Past research indicates respite services are commonly a high concern to caregivers of persons living with dementia (Gottlieb & Johnson, 2000).

Past research shows that up to 40% of stress related to caregiving is reduced with the use of respite care, such as adult day services (ADS) (Zarit, Kim, Femia, Almeida & Klien, 2013).

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Adult day centers provide services to adults 60 years or older who are able to move around by either walking or with the use of a wheelchair and who are currently living in the community with family caregivers (Cheung & Ngan, 2007). Socialization, medical care, health monitoring, therapeutic activities and transportation are some things that adult day programs can provide (Gaugler et al, 2003). Examples of other services provided by adult day programs are meeting personal care and attention needs, providing meals, family caregiver support and education (Cheung & Ngan, 2007). Services like adult day “play an important role in the continuum of community support services and residential services” provided to older adults (Cheung & Ngan, 2007). Adult day programs are one of the few ways caregivers can be given respite from caregiving duties for several hours of the day thereby helping to alleviate burnout (Gaugler et al, 2003).

Social workers play a pivotal role in working to identify and mitigate the burnout caregivers of persons with dementia in the community experience. Through their education and training, social workers are “uniquely qualified” to provide a number of services within adult day centers (Choi, 2013, p. 3). Qualifications may include: assessment and care planning; outreach services; case management; program design; implementation and evaluation; family and individual counseling; assistance accessing in-house and community volunteer and transportation services, among others (Choi, 2013). There are few studies that address a social worker’s role specifically in supporting caregivers within the adult day setting. However, from previous research, it is known that caregiver support is an integral part of creating sustainable community services for older adults with dementia and their caregivers.

The purpose of this research study is to better understand how social workers within adult day settings identify burnout in the caregivers they serve and how to better support their needs.

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Through the use of the conceptual framework of ecological theory, this study aims to explore the ways adult day social workers identify and help mitigate caregiver burnout. Due to the prevalence of dementia among older adults as well as the predicted increase in persons with dementia over the next 50 years, the number of informal and familial caregivers are expected to rise to meet the need. Therefore, it is vital that the social work profession examine how to best support caregivers, not only for best practice but also for creating and maintaining sustainable community services for older adults.

Literature Review

Recognized by the literature as a duty that is most often performed by family members, the informal/familial caregiver and person with dementia relationship has been extensively documented in previous studies. For this study, the literature review focused on familial caregivers of persons living with dementia (PWD) and the role social workers play in providing support through identifying and mitigating burnout experienced by caregivers.

Family support persists as a significant resource for older adults living in the community (Gitlin, Reeve, Dennis, Mathieu & Hauck, 2006). In 2006, it was estimated in the United States that family caregivers provided 80% or more of long-term care services to older adults (Gitlin et al, 2006). Care needs increase over time due to dementia's progressive nature (Tretteteig, Vatne, & Mork Rokstad, 2016). Often and over time, family members become around the clock caregivers to their elder relative with dementia (Tretteteig, Vatne, & Mork Rokstad, 2016).

The research on adult day care service utilization shows the service is under used, and research has extensively repeated this finding. Substantial research also reflects the challenges

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and stressors that can go along with being a caregiver of an individual with dementia. It is also known that support systems like case management and family counseling or support groups play a role in decreasing symptoms like depression and increasing confidence. However, the research on the specific role of social workers in supporting familial caregivers within adult day services is limited.

Demographics of dementia

One of the largest growing public health concerns, not only in the United States but worldwide, is dementia (Kim, Chang, Rose, & Kim, 2011). The majority of PWD will need assistance, which typically falls on family members to fulfill (Papastavrou et al., 2011). In 2012, it was estimated that 17.5 billion hours of unpaid care was provided by 15.4 million Americans to individuals living with dementia (Jennings et al., 2015). The number of people who will need assistance is expected to rise with the baby boomer generation (Anderson, Dabelko-Schoeny, Fields, & Carter, 2015).

As dementia progresses, it triggers the need for increased and more consistent assistance, typically from family members (Tretteteig, Vatne, & Mork Rokstad, 2016). Throughout the progression of the disease, persons with dementia are likely to experience at least one of the following: paranoia, depression, agitation, elation, trouble sleeping, hallucinations, restlessness, and delusions (Yeager, Hyer, Hobbs, & Coyne. 2010). These experiences are worrying to familial caregivers, lead to a higher acuteness of assistance and are linked to early placement (Yeager, Hyer, Hobbs, & Coyne. 2010).

Familial caregiver and dementia

Providing care for family members dates to the earliest years of humanity (Link, 2015). The familial caregiver can be a spouse, adult child, in-law or close relative (Noelker & Browdie, 2012). The term caregiver encompasses a variety of actions or assistance. Caregiving is typically defined as “persons who assisted individual with at least one activity of daily living” (Kim, Chang, Rose & Kim, 2011, p.848). Caregiving can also mean helping to manage finances, household or outdoor chores, and regular check in’s to make sure the individual is okay (Kim, Chang, Rose & Kim, 2011). In 2015, it was estimated that between 2014 and 2015, 34.2 million Americans assisted in caring for an adult over the age of 50 (National Alliance for Caregiving, 2015).

A 2015 study reported that over 50% of caregivers are female, and most are middle age; however, 7% are persons 75 or older (NAC, 2015). In the same study, 22% of caregivers reported their loved one whom they provide care for has a form of dementia (NAC, 2015). Many caregivers are not expecting to be caregivers before the duty, and the reality of the role comes as a surprise (Williams, Morrison, & Robinson, 2013). Even so, caregivers are often devoted to ensuring their relative can remain in the community (Link, 2015).

Family caregivers who provide in home care to a relative with dementia often experience burnout. Caregivers of persons with dementia are noted to experience more burden than non-dementia caregivers (Kim, Chang, Rose, & Kim, 2011, Yeager, Hyer, Hobbs, & Coyne, 2010). This increased amount of burden is attributed to the amount of daily time spent caregiving and the level of assistance required to complete daily activities of living (Yeager, Hyer, Hobbs, & Coyne, 2010). Challenging behavioral issues that can occur make the challenge of caregiving greater with PWD than non-dementia caregiving (Hurley, Patterson & Cooley, 2014).

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Additionally, caregivers are called to provide personal care and supervision of PWD, which often fosters depression, difficulty managing work, dwindling finances, burnout and strain on caregivers as the disease progresses (Jennings et al., 2015).

Burnout/Burden

Caregivers experience a complex set of emotions throughout the caregiving experience and disease process of the PWD. Research over time has indicated that the role of caregiver to a family member is stressful (Schreiner, Morimoto, Arai, & Zarit, 2006). A 2011 study, reports that the caregivers most at risk are spouses, those who are advanced in age, women, and caregivers who share a residence with their relative (Kim, Change, Rose, & Kim, 2011). Other factors linked with caregiver burden include ability to cope, type of assistance needed, and level of support (Kim, Chang, Rose, & Kim, 2011). Caregiver burden affects not only the physical and psychological well-being of the individual/s but also the financial and social aspects of daily life (Kim, Chang, Rose, & Kim, 2011, Tretteteig, Vatne, & Mork Rokstad, 2016). Family caregivers experience their complex role in unique ways (Williams, Morrison & Robinson, 2013).

Family caregivers who provide in home care to a relative with dementia often experience burden. Caregiver burden is defined as a multifaceted concept that fluctuates between primary and secondary stressors (Schacke & Zank, 2006). Primary stressors include challenging behaviors, emotions or functioning ability and daily tasks of caregiving, whereas secondary stressors are areas outside of caregiving such as work, social life, caregiver health and family (Schacke & Zank, 2006, Tretteteig, Vatne, & Mork Rokstad, 2016, Zarit, Femia, Kim, & Whitlatch, 2010). Caregivers must learn to manage their relative's loss of cognitive function over time, increasing personal care needs, and challenging behaviors (Papastavrou et al, 2011). The most commonly reported behavior of PWD is agitation or aggression (Jennings, Reuben et

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al, 2015). PWD can also experience decreased ability to communicate and personality changes over time (Jennings et al., 2015).

In comparison to non-caregivers, caregivers use more prescription medications, healthcare services and experience more psychological and physical ailments (Kim, Chang, Rose, & Kim, 2011). High levels of these stressors can lead to harmful impacts on caregivers, such as increased health problems, burden, social isolation and depression (Papastavrou et al, 2011). Caregivers can also be at an increased risk for anxiety and financial difficulty (Tretteteig, Vatne, & Mork Rokstad, 2016). Concerns regarding the quality of their life, depression and poor coping strategies are common for caregivers (Kim, Chang, Rose, & Kim, 2011). One study reported that 25-50% of caregivers meet the criteria for a depressive disorder (Yeager, Hyer, Hobbs, & Coyne, 2010).

Caregiver coping

Caregivers find unique and individual ways of coping with the challenges of caring for a relative with dementia. Relief is a common experience when loved one receives a dementia diagnosis, there is often a long period of suspicion that becomes confirmed (Williams, Morrison, & Robinson, 2013). An official diagnosis allows caregivers to come to grips with the disease and begin to form solutions to challenges that result from dementia (Williams, Morrison, & Robinson, 2013).

A study in 2013 reported a wide variety of ways caregivers identified as tools for coping. Normalizing the struggles of caregiving with other caregivers is a way for caregivers to feel less isolated and that the challenges are more universal (Williams, Morrison, & Robinson, 2013). The 2013 study reported that when caregivers felt unable to adjust challenging aspects of their

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relative's dementia, they had a propensity to look to the silver lining of the situation or appointed inner acceptance (Williams, Morrison, & Robinson, 2013). When feeling helpless, humor was one way some caregivers chose to cope (Williams, Morrison, & Robinson, 2013). Others sought a sense of control over the challenges by organizing, requesting information and planning, which some felt also elicited more free time (Williams, Morrison, & Robinson, 2013).

Feelings of helplessness also extracted avoidant coping behaviors from a few caregivers, especially when feeling a poor quality of life for themselves or their relative and loss of control (Williams, Morrison, & Robinson, 2013). Avoidance appeared more favorable and adaptive for caregivers with relationships that were considered poor before the caregiving began (Williams, Morrison, & Robinson, 2013). Other caregivers reported ceasing to bring their relative to social events or public places or camouflage them if they did as an attempt to maintain their relative's dignity and protect both themselves and the relative from humiliation or embarrassment (Williams, Morrison, & Robinson, 2013). However, a 2006 study reported that caregivers felt more confidence in their ability to provide care when provided with support from ADS (Gitlin et al, 2006).

Caregivers on support

With the challenges of caregiving for a PWD, support is essential. Past research shows that caregivers' experience and attitude towards support varies. For some caregivers, support from other family members is vital to continue their role (Williams, Morrison, & Robinson, 2013). Other caregivers reported feeling their position was rewarding and they felt more motivated when their care recipient showed gratitude or acknowledgment of their needs, or if the care was reciprocated in some way (Williams, Morrison, & Robinson, 2013). There is a noted strain on caregiver motivation when care recipients' ability to reciprocate in some way is limited

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or no longer possible (Williams, Morrison, & Robinson, 2013). Community based services like ADS are another avenue of support for caregivers and their families.

Respite

One way of limiting the stress or burnout associated with caregiving for a PWD is to get respite from caregiving duties. One of the most discussed provisions of ADS is respite from caregiving duties for caregivers (Anderson, Dabelko-Schoeny, Fields, & Carter, 2015, Tretteteig, Vatne, & Mork Rokstad, 2016, Gitlin, Reeve, Dennis, Mathieu and Hauck, 2006, Cheung & Ngan, 2007, Link, 2015). Respite care can be provided in an adult day center, residential facility, or in the individual's home and the term is used interchangeably between these settings (Tretteteig, Vatne, & Mork Rokstad, 2016).

There are a number of reported reasons caregivers use respite services like ADS. Avoiding nursing home placement, numerous benefits for the PWD, relief from caregiving duties are the primary reported reasons for ADS use (Zarit, Parris Stephens, Townsend, Greene & Leitsch, 1999).

Adult Day

Adult day services (ADS) are one of many community-based resources for older adults and their families. Russia and Canada were some of the first countries in which systems of day care for older adults were established and consisted of care in psychiatric day hospitals (Dilworth-Anderson & Hildreth, 1982). ADS has grown over time to play a large role in community-based services (Cheung & Ngan, 2007). A 2015 study reports ADS is a leader in community-based programs for individuals living with dementia and their families (Anderson, Dabelko-Schoeny, Fields, & Carter, 2015). As of 2015, "there are over 4,600 ADS centers in

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operation serving an estimated 260,000 participants and families” in the United States, marking an increase of 35% in centers between 2002 and 2015 (Anderson, Dabelko-Schoeny, Fields, & Carter, 2015, p.102). A factor of this comes from changes in policy that promote home-based services over residential facilities to meet the needs of older adults (Tretteteig, Vatne, & Mork Rokstad, 2016). Policy makers view ADS as affordable and practical option for community based care (Anderson, Dabelko-Schoeny, Fields, & Carter, 2015).

ADS on the whole, provide community based services which target such needs as socialization, therapeutic activities, observing health issues, medical care and transportation for older adults (Gaugler et al, 2003, Anderson, Dabelko-Schoeny, Fields, & Carter, 2015). Individuals typically spend at least 4 hours during the day at ADS, where there are paid staff and volunteers to meet the group’s needs and then recipients return home at the end of the day (Tretteteig, Vatne, & Mork Rokstad, 2016). ADS has long focused on the needs of PWD and also responded to the growing need for services focused on dementia care (Anderson, Dabelko-Schoeny, Fields, & Carter, 2015).

Along with the benefit ADS programming offers PWD, there are additional benefits for their caregivers. Many ADS programs provide psychological support to families and caregivers, which facilitates in maintaining caregivers ability and confidence to provide care at home (Dilworth-Anderson & Hildreth, 1982). Support and empowerment of caregivers is vital because at the end of the day caregivers are providing care at home (Cheung & Ngan, 2007). ADS assists in allowing PWD to remain in the community longer by providing a place for them to go during the day that in turn relieves the caregiver of responsibility and reducing strain (Zarit, Parris Stephens, Townsend, Greene & Leitsch, 1999). Respite and providing supportive services are

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two ways ADS assist in supporting caregivers (Anderson, Dabelko-Schoeny, Fields, & Carter, 2015).

Considering what the literature says about caregiver burnout and ADS, it is worth further study to discover how social workers view their role in identifying burnout and providing additional resources, support, or education to caregivers. The research question for this study is: What is the role of adult day social workers in identifying and mitigating caregiver burnout?

Conceptual Framework

This section will discuss the theoretical framework that influences the organization of the research study, which is ecological systems theory. For the purpose of this study, ecological systems theory is used as a lens for developing the research. This lens will then play a guiding role in the interpretation of the data and as a means to evaluate the study. The ecological systems model is composed of four levels: microsystem, mesosystem, exosystem and macrosystem (Onwuegbuzie, Collins, & Frels. 2013). In qualitative research, typically only one level is examined (Onwuegbuzie, Collins, & Frels. 2013). The level of ecological systems theory that relates to this qualitative study is the mesosystem. The mesosystem is defined as “the interrelations among two or more settings in which the person actively participates among family, work and social life” (Onwuegbuzie, Collins, & Frels. 2013, p.4).

The purpose of this research study is to better understand the interrelations between family caregivers and the adult day social workers who provide them with support. By applying the conceptual framework of ecological systems, specifically the mesosystem, this study seeks to examine the role social workers have in identifying and understanding caregiver burnout and finding unique ways to support caregivers. It is crucial for social workers in adult day programs to understand their role in providing support to family caregivers and be able to identify the individual ways caregivers display burnout, verbally or non-verbally.

Methods

Research Design

This descriptive study utilized a qualitative design for data collection in order to answer the research question, “what role do adult day social workers have in identifying and mitigating caregiver burnout?” A qualitative method was well suited for this study because the research sought to collect and analyze data from the standpoint of an individual living the experience (Monette, Sullivan, & DeJong, 2008). More specifically, this qualitative research aimed to obtain a deeper understanding of the topic that can only be derived through participant’s who are living the experience (Padgett, 2008).

This qualitative study depended on a semi-structured interview technique developed with open-ended questions. The researcher found eight social workers currently working in an adult day center setting through snowball sampling. The interviews lasted between twenty-two minutes to fifty-five minutes in private meeting areas specified by the participant’s preference. All interview participants preferred to conduct interviews in a conference room or office of the adult day center they worked at. A series of three introductory questions and eleven focused questions that used a semi-structured format (See Appendix A) were asked and interviews were digitally recorded. The researcher kept field notes as a documentation of key insights and observations. The interviews were then transcribed and analyzed using grounded theory to further understand participant’s responses. The researcher then coded each answer or phrase to discover overall themes, sub-themes and categories.

Sample

The sample for this study consisted of eight participants. The participants in this study were chosen based on their current position as a social worker in an adult day setting in the Twin Cities Metropolitan region. There was no limitation to the level or classification of the license each social worker holds as long as each participant is actively licensed. The eight social workers that were interviewed all held social work licensure, two held an LICSW, one held an LGSW, and five held an LSW license. All interviewees worked in adult day settings, seven worked on site at the day center, and one worked off-site providing most services via phone or email and through a monthly support group. All eight participants have experience facilitating a caregiver support group, however, only six participants reported they were currently running a support group for their position at the adult day center. All eight respondents were white females who work and live in the Metro Twin Cities area of Minnesota.

Participants were initially gathered using a convenience sample procedure through professional contacts and colleagues. Convenience sampling is a procedure that gathers samples from readily available sources (Monette, Sullivan, Dejong, & Hilton, 2014). Four participants were found using the convenience sample procedure and when participants were no longer emerging the researcher switched to snowball sampling method. Snowball sampling, was completed by participants offering the contact information of another potential participant or being asked if they know any other adult day social workers. Four other participants were gathered through snowball sampling. The researcher sent all potential participants a letter describing the research via email (see Appendix B). The letter was emailed to potential participants individually once contact information was obtained. The letter explained the study, the approximate length of the interview, a statement regarding confidentiality and provide the

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researchers contact information so that potential participants who are interested can reach out to the researcher. All participants were offered a \$5 gift card to a local coffee establishment upon completion of the interview.

Protection of Human Subjects

The protection of human subjects was guarded and maintained by a number of measures to ensure research was conducted ethically. This research study was guided under the supervision of Rajean Moone, PhD., LNHA, adjunct professor of Social Work at St. Catherine University and the University of St. Thomas School of Social Work. This project met the approval of the St. Catherine's University Institutional Review Board (IRB) prior to interviews taking place.

An informed consent form (see Appendix C) was developed and used with all participants. The form was provided to all participants prior to beginning each interview, ensuring the opportunity to answer any questions. Participants were asked to read the consent form and voice any questions for the researcher before signing the consent form. The consent form briefed participants on the purpose of the study, the reason for being selected, the process of the interview and how the data would be used. Participants were also asked to briefly describe what the purpose of the study was as well as what they are being asked to do, to ensure full understanding. The researcher discussed and emphasized the completely voluntary nature of participation in the study and that it would have no impact on their position with the organization they work for.

Each participant received a copy of the signed consent form for their own records, which included the contact information for the researcher, the researcher's supervising professor and the St. Catherine University Institutional Review Board. Participants were advised that there

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would be no direct benefits from their participation in the study. The researcher also informed participants of the minimal risk involved with this study, but informed them of the possibility of some questions to be uncomfortable or distressing. The researcher provided participants with the 2-1-1 hotline number to contact if any distress occurred post interview.

Confidentiality was of the utmost importance. Communication between the researcher and participants was done through password-protected email. All records were kept confidential and did not include any identifying information. For each interview, the study included a digital audio-recorded voice file, a typed transcript completed by the researcher and hand written notes taken during the interview. All digital files, including the typed transcripts, were kept on the researcher's personal laptop that is password protected and hand written notes were kept in a locked file cabinet that only the researcher has access to. The researcher will destroy all digital audio recordings, typed transcripts and hand written notes by June 30, 2017. Federal guidelines request consent forms to be kept for three years following the completion of research. The consent forms will be kept in a locked filing cabinet to which only the researcher has access to.

Data Collection

This qualitative study focused on using a semi-structured interview design to gather data from its participants. The interviews were conducted face-to-face and lasted between 22 minutes to 55 minutes. In order to address the research question, the interview consisted of 14 questions (see Appendix A). The researcher began by asking basic demographic information as a way to build context and followed by asking 11 open-ended questions. Open-ended questions were used to provide for possible spontaneity and variances in participants responses. The location of each interview was determined based off the preference of the participant. The location was also determined by its capability to provide privacy and confidentiality. All participants preferred to

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conduct the interview at the adult day center they worked at, either in a conference room or in their personal office. All spaces upheld the ability to maintain privacy.

The list of interview questions was provided to participants five days before the interview as a way to focus the interview and gain robust responses from participants. The researcher constructed these questions after a review of the literature regarding informal/familial caregivers of persons with dementia and adult day services. The primary interview questions asked the participants to discuss the signs they identify as burnout in caregivers, the challenges caregivers often encounter, common ways they provide support to caregivers, education that's typically provided to caregivers, additional resources offered and what helps caregivers maintain their role over time.

Once the researcher had identified a participant as interested and eligible, a meeting was set up as outlined above. The informed consent was presented and completed per the procedure outlined. The interview began once the informed consent was completed along with the participant's agreement for the interview to be digitally recorded and for the researcher to take brief notes. The researcher provided time at the end of the interview for the participant to ask any further questions and provided the 2-1-1 contact information. The session ended when the participants indicated she was comfortable to do so. Following the interview the researcher transcribed all interviews verbatim, omitting any identifying information.

Data Analysis

The researcher analyzed the data from the interviews by transcribing each interview word for word, matching every question with the response. The researcher for the purpose of analysis exercised a grounded theory methodology approach to data. Data analysis began with using an

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open-coding process, which lead to selective coding. This was appropriate for the study because it allowed themes and concepts to surface from codes, thereby allowing the researcher to make connections between commonalities in participant's experiences to further explore the research question.

The first analysis of the transcripts focused on viewing them through the conceptual framework of ecological systems theory, specifically through the lens of the mesosystem. After reviewing all eight transcripts as a whole, each transcript was evaluated individually, piece-by-piece to pull codes and themes from the participant's responses. Identifying codes lead to the researcher to narrowing down themes in the data. Themes and corresponding sub-themes were identified and gathered by patterns of similar or repetitive responses. Themes were then analyzed with the literature review to compare likeness and conflicting data.

Strengths and Limitations

This qualitative study has many strengths due to its design. Previous research on informal/familial caregivers of persons with dementia guided and supported the interview questions. Therefore, a comparison between the findings of the study and others may easily be made. Interview questions were also peer-reviewed and written clearly to promote quality. Before the interview, the research participants received the interview questions via email. This gave the participants an opportunity to review the questions, provide in-depth responses during the interview and also add to any points that may not have been covered by the questions. In turn, this method provided robust information on the complex topic of relationships between caregivers and their loved ones as perceived by adult day social workers. Open-ended questions were used, instead of leading questions, to refrain from the possibility of the researcher's bias

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coming through in the interview. Offering a gift card assisted in attracting participants, thereby strengthening the number of participants and variation of responses.

In addition to strengths, there were also a number of limitations to this study. The main limitation of this study was the small sample size that was utilized through snowball effect method to gather participants. Another limitation is that the study was only conducted in the Twin Cities metropolitan region. This means excluding the experiences of social workers in other states where adult day services potentially differ as well as excluding rural area social workers experience, which could vastly differ from that of an urban or suburban social workers experience. Using the snowball effect method with a small sample size, generalizations across all social workers working in adult day setting could not be made from the data. Caregivers were not interviewed due to time constraints; therefore the unique and valuable perspective of burnout from caregivers themselves lacked from the data. An additional limitation that was discovered while searching for potential participants is that not all adult day centers have a licensed social worker on staff. Although the researcher was able to meet the minimum goal of 8 participants, many adult day centers in the metropolitan area did not have a social worker.

Findings

This study was designed to explore the ways adult day social workers identified and mitigated caregiver burnout. During data analysis, four themes stood out with subsequent sub-themes emerging from each theme. The four themes were: definition of burnout, causes of burnout, burnout reduction as multi-pronged approach and formal supports as interventions. Within the theme of definition of burnout six sub-themes of: overwhelmed, crying, exhaustion, appearance, guilt and anger were identified. Four sub-themes within the theme of causes of burnout were identified: dementia behaviors, role overload, lack of sleep, and lack of support. The theme of burnout reduction as multi-pronged approach diverted into eight sub-themes of sitting in the moment, encouragement, and informal check in's and normalizing, of dementia process, self-care, future planning, and how to ask for help. Within the theme of formal supports as interventions, four sub-themes emerged: community resources, support group, caregiver coaching, and respite. Table 1 offers a visual representation of themes and corresponding sub-themes.

Themes	Definition of Burnout	Causes of Burnout	Burnout Reduction as Multi-pronged Approach	Formal supports As Interventions
Sub-Themes	Overwhelmed	Dementia Behaviors	Sitting in the Moment	Community Resources
	Crying	Role overload	Encouragement	Support group
	Exhaustion	Lack of sleep	Informal Check in's	Caregiver coaching
	Appearance	Lack of support	Normalizing	Respite
	Guilt		Dementia process	
	Anger		Self-care	
			Future planning	
			How to ask for help	

Table 1. Themes and sub-themes

Definition of Burnout

Participants were asked to describe their definition of burnout and the signs they associate with caregivers who are burnt out. Six sub-themes were identified from participant's responses of the complex emotions and physical signs that can be indicative of burnout. These sub-themes came forward from participant's statements about verbal statements they hear from caregivers or non-verbal signs they observe during interactions with caregivers. Feelings of being Overwhelmed, guilt, crying, exhaustion, appearance and anger were all identified as verbal and non-verbal indications within the definition of burnout participants reported.

Overwhelmed. When asked what burnout looks and sounds like, participants broadly discussed feelings or indications of being overwhelmed as the main sub-theme that emerged. Caregivers feel overwhelmed with the task of caregiving and are often at a loss of how to move forward or strike a balance in their role as caregiver. Six participants discussed the different signs that indicate to them that a caregiver is feeling overwhelmed. Participant 2 stated: *"Caregiver burnout to me is a combination of stress at being overwhelmed at the task and not seeing any solutions or not having any support to help them with the task"*.

Participant 7 stated: *"Another sign when you know the caregiver is so overwhelmed they can't remember things, they can't follow through with things, and everything is so overwhelming to them that they can't take the next step"*.

Participant 6 stated: *"They're at their wits' end, they don't know what to do...they're just kind of completely frazzled"*

Participant 1 stated: *"They might verbally say I don't know how much longer I can do this."*

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Participant 5 stated: *“I think you see people that are burnt out pulling way back and saying I just cant do this...they don’t have it in them to care anymore.”*

Participant 8 stated: *“Someone that is just on the edge, someone that is barely making it, barely getting by, just living day to day.”*

One participant described the definition of caregiver burnout she imagines. Participant 3 stated: *“I think I just picture this overwhelming paralysis...I can’t think, I don’t even want to think about or make a decision for what I want for supper vs. caring.”*

Guilt. Four of the participants described caregiver’s feelings of guilt as coming from their wish to be the sole supporter of their care recipient, internal pride and beginning to realize they need help. Participant 1 stated: *“Guilt, that’s huge and part of the whole thing, even as much as going to an adult day center, how much that helps the caregiver cause there getting respite, there’s still guilt that well I can’t do it all.”*

Participant 3 stated: *“They are very proud and there’s a lot of guilt with not being able to do what they want to do for this person that they love.”*

Participant 4 stated: *“I think if there’s guilt you know that they express that. They’re feeling guilty about trying to get their person enrolled in using services, guilty about reaching out for help, if they’re trying to do it all.”*

Participant 8 stated: *“Them (caregivers) not taking time for themselves, that is a hard thing to persuade them to do because of the guilt that they feel like they have to do everything.”*

The other participant, participant 7 described caregiver’s feelings of guilt as stemming from caregivers questioning how others viewed their ability to provide care, stating: *“I think*

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there's a lot of guilt, they think that people are questioning anything that they are doing and maybe there thinking there not doing it right."

Crying. Crying can be an indicator of a multitude of emotions; in this case, five participants identified crying as a physical and emotional sign of burnout among caregivers. Participant 2 stated: *"It shows up in some emotional weepiness and I would say that's for both genders. Guys that will get kind of misty eyes about their wife not being who she once was."*

Participant 4 stated: *"Crying, you know that sort of thing."*

Participant 5 stated: *"Yeah, crying, I mean this particular person I just told you about cry's a lot with me when we talk."*

Participant 7 stated: *"You see it right away you know when their eyes fill with tears."*

Participant 8 stated: *"Sometimes they'll come in and they'll have tears in their eyes, they'll pull me aside and say its been a rough night."*

Exhaustion. While caring for an older adult and the complex set of needs that can occur, exhaustion is common among those who are extremely burnt out from the demands of caregiving. Three participants described the indicators they see in caregivers who are exhausted. Two participants talk about exhaustion as a physical appearance. Participant 1 stated: *"Physically caregivers will come in and look exhausted, you ask them how they are and they just start crying. Not just physical exhaustion, emotional, spiritual exhaustion, they're just so full and overwhelmed"*.

Participant 2 stated: *"The people that I see that are really burnt out they have either just been doing it so long they've got a physical component where their exhausted."*

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One participant described exhaustion as a definition of burnout that included a change in the caregivers attitude: *“I think it’s a state of physical, emotional and mental exhaustion that may be accompanied by a change in attitude from positive and caring to negative and uncaring.”*

Appearance. Physical appearance can be an indication of caregiver burnout, things such as lack of grooming and body language. Four participants indicated that appearance is a red flag for them that something may be going on with the caregiver and a reason for them to check in with the caregiver. Three participants talked about the lack of grooming as an indication. Participant 4 stated: *“The appearance, the caregiver not looking as groomed and not taking care of themselves.”*

Participant 7 stated: *“I see caregivers not taking care of themselves, you know you can tell, maybe there personal grooming isn’t as good as it used to be when you first met them.”*

Participant 8 stated: *“Some of them look kind of frazzled in their appearance, like they just haven’t taken time to put themselves together.”*

One participant discussed the appearance of burnout as body language. Participant 2 stated: *“It looks like slumped over hopeless body language.”*

Anger. Four participants described anger as an indication of caregiver burnout and discussed various ways anger is expressed. Participant 5 discussed the ways she sees burnout in a general manner: *“It sometimes comes out in depression or anger or lack of patience.”* Participant 2 described a caregiver who was angry at baseline and once knowing more about the anger, her response in support to the caregiver, by stating: *“(caregiver) Always presented herself as angry...to find out she’s angry at her spouse for having this disease because that means he’s not living up to his end of the marriage bargain...also giving her a place to talk about being angry”.*

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Participant 1 related the anger she has seen from caregivers to unidentified feelings of grief, stating: *“When I’m hearing or seeing a lot of anger with a caregiver and I think tied into that burnout question is grief, I think that’s part of it and the caregiver is not identifying that what is happening to them is their grieving and that’s why their angry”*.

Participant 3 reported she identifies anger through tone of voice and attitude that caregivers present through interactions, by stating: *“Verbally getting short with their loved one or with us or with anyone and they typically aren’t that way...if someone typically isn’t that way and they are then that’s a cue for me that something is going on.”*

Causes of Burnout

Causes of burnout emerged from the data as the second theme and led to four sub-themes. The sub-themes were identified through participant’s statements regarding challenges of caregiving they hear most often from caregivers. Dementia behaviors, lack of sleep, lack of support and role overload were identified from challenges that caregivers who are burnout bring up in conversations or from statements they make during interactions.

Dementia Behaviors. As the disease progresses, people living with dementia can experience changes in their normal behavior and responses to the world around them; this can create challenges for those providing daily care. Three participants discussed the various ways caregivers talk about the challenge of behaviors while caring for someone living with dementia. One participant describes caregiver’s responses to the behavior in public and in turn how she attempts to alleviate their stress. Participant 2 stated:

“I’ll see lots of caregivers that when they come here for the first time to tour even they’ll start kind of like apologizing to us for their parents behavior or we say we got this

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activity and they're like well my moms got dementia and she probably wont be able to participate, I'm like no we get it, but it think that probably caregivers go around apologizing a lot whether they're out in public, different settings, for their loved ones behavior for not fitting in so to know that somebody understands and gets it I think is pretty empowering."

Two participants reported that caregivers who are burnt out often bring up a variety of challenges, with cares or communication; they are having with the person living with dementia's behavior. Participant 8 described challenging behaviors from a caregiver with a wife who has dementia as repetitiveness, sundowning, and aggression: *"His wife is particularly challenging with behaviors, a lot of repetitiveness, some aggression, she has sundowners, so she gets in the evening she gets kind of restless, wants to go home, looking for her family, that sort of thing."*

Participant 1 stated: *"I'll have caregivers, just so many recently saying, I can't even go to the bathroom or my wife is crying wondering where I am...I can never be out of her sight."*

Lack of Sleep. Difficulty sleeping through the night was a common thread among three of the participants and was a result of individuals with dementia not sleeping or wandering at night or older adults needing help from caregivers to use the bathroom. Four participants discussed the challenges they hear from caregivers with sleep deprivation. Participant 1 stated: *"I hear that so often that the person living with the disease is not sleeping therefore the caregiver is not sleeping"*.

Participant 2 stated: *"It shows up in sleep disturbances and that can be because your laying awake at night thinking about what's going on and the stressor or you're laying awake at*

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night waiting to hear somebody walk down the hall and get in the fridge. Sleep deprivation takes its toll pretty well.”

Participant 5 stated: *“Not getting enough sleep, their loved ones keeping them up or waking up a lot or needing to go to the bathroom a lot or kind of having confusion that increases at night.”*

Participant 7 stated: *“The biggest thing we hear is with caregivers is, especially those with, that there caring for have dementia, that the night time is really difficult because there not getting sleep because the loved one is up and rummaging around the house, they’re afraid they’re going to walk out the door.”*

Lack of Support. Multiple participants described struggles they have heard from caregivers, the lack of support from other family member or adult children in helping with duties and tasks of caregiving. Three participants talked about caregivers reporting a lack of support as a challenge.

Participant 1 reported: *“Lack of support from other family members, the caregiver feels like they’re all alone in this and they’re not and so they’re angry cause they’re not getting support from their adult children or other family members and it’s all on them”.*

Participant 2 stated: *“Children who are reluctant to step in and make so many decisions for their parent, as their parent has more and more challenges.”*

Participant 4 stated: *“Not having a lot of other support you know where siblings aren’t there or it’s a dysfunctional family, there not talking to each other.”*

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Role Overload. The role overload was comprised of lack of freedom, wanting to do it all, taking on tasks the care receiver used to complete, and learning to accept help or ask for help from others to minimize overload. Four participants discussed this sub-theme in regards to common challenges caregivers bring up in conversation. Participant 1 described care partners feeling trapped in their role and making statements to her such as *“All the things I used to do that I enjoyed I can’t do anymore, I can’t leave home, I feel like a prisoner in my own home”* and *“I have no time for myself, I’m just doing everything.”*

Participant 5 also discussed the lack of freedom that caregivers express due to the demands of the many roles they fill as caregivers: *“Lack of freedom to do what they like to do, it’s hard for them to get things such as groceries and get to the pharmacy and hard for them if they work part time, hard to sometimes make work and caregiving all happen at the same time.”*

Participant 8 described a challenge for her that stems from the caregivers wanting to do it all by stating: *“I think the biggest challenge is persuading people that it’s okay to give up care to other people so they can take a break”*. The same participant also reported that some caregivers struggle with seeing or perceiving the difficulty they are having due to being in *‘caregiver mode’*.

Participant 7 described a situation working with a caregiver experiencing an over load in the multiple roles she was trying to fulfill: *“So she’s at a loss you know, she’s always been very independent, she’s always done her own things, they both had very busy careers, she’s still working, she was just very distraught, didn’t know what to do.”*

Burnout Reduction as Multi-pronged Approach

When asked to define their role as a social worker in the adult day setting, eight participants expressed being a source of support and providing education as important. Participants were asked to describe the types of informal support and education they provide to caregivers. Four sub-themes emerged from participant's responses of the support most often provided. The sub-themes include: sitting in the moment, encouragement, informal checks in's, and normalizing. Sub-themes of education that emerged from their response included various aspects of the dementia process, the importance of self-care, teaching caregivers how and when to ask for help, and planning for the future.

Sitting in the moment. Three of the eight participants described being present in the moment with caregivers and allowing them to express their feelings as a way to support their needs at the moment. Participants talked about many caregivers not having an outlet to share their feelings outside of adult day services, or support groups and the need caregivers have to feel like someone listens to them.

Participant 1 stated: *"If they are angry I let them be angry cause they need to get that out."* Participant 1 also stated: *"Whatever it is they're feeling first of all I validate that and we talk about that, it's how they're feeling and it's real."*

Participant 2 discussed her most common response stated: *"I guess the consistent thing is I try to help people feel heard."*

Participant 8 stated: *"A lot of times I just let them vent and at the end I will tell them you know your doing a good job."*

Encouragement. Six participants described providing encouragement regarding validation, acknowledgment, recognizing expertise and strengths and they do this repetitively

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over time. Participants gave a variety of responses. Participant 1 described how she responds to caregivers as experts and tries to acknowledge successes along the way, by stating:

” They’re the expert on their situation...so starting with that rather than me listing a bunch of things they could try. Exploring with them what has worked or looking to them to help problem solve how to manage the situation. I think it’s important for us as social workers helping them to see what they maybe aren’t seeing as a success...acknowledging all that they’re doing and how well, cause caregivers think they’re not doing enough all the time.”

Participant 6 reported her use of acknowledging caregivers as experts and teachers stating: *“I always tell caregivers that you guys are the experts, that you guys are the ones that have taught me how to be a better social worker.”*

Participant 2 discussed her role in acknowledging strengths that caregivers may not realize they possess, by stating: *“It’s not enough for me to say well I’m going to give you a brochure or a list of ten places you can call, it’s helping them to kind of explore what resources do they have, resiliency, and kind of pulling those things out because people do have more strength than they know.”*

Participant 3 discussed her approach to encouraging caregivers to use more supportive services when she observes burnout, by stating: *“I think just being sort of that squeaky wheel with her but a gentle squeaky wheel, you know, so I don’t feel like I’m hounding her.”* Participant 3 also stated in regards to how often she provide encouragement *“You try to do it whenever you can cause people don’t hear it enough.”*

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Two other participants reflected on the reason of acknowledging and thanking caregivers for their efforts. Participant 4 stated why she believes it's important to offer encouragement: "*It's to support that caregiver to be able to continue to do what they do for that loved one.*"

Participant 5 discussed the response she most often gives caregivers: "*Thank our caregivers for what they do because I think it's a thankless job.*"

Normalizing. Before being involved with supportive service or support groups, the experience of caregiving for a person with dementia can feel isolating. Two participants talked about the support they give to caregivers who are struggling with the use of normalizing their situation. Participant 2 stated: "*Helping to normalize their situation...if there's not a lot of caregivers around or they don't see anyone else that's struggling with dementia they wonder are they going crazy, what's wrong with them, they can't cope.*"

Participant 6 stated: "*I think normalizing people's experience cause I think a lot of times people feel very alone and isolated.*"

Informal check in's. Informal check in's were defined by participants as typically brief encounters, either at the center during drop off/pick up, check in phone calls or a meeting outside the quarterly meeting requirement. All eight participants stated these informal encounters and chances to provide on the spot support occur most often and are a way to get a read on how caregivers are doing. Topics that participants say come up include crisis work, assessment, problem-solving, Two participants described most of their informal support as being over the phone due to either transportation bus that brings most members to and from the adult day center or the participant not having an office on site at an adult day center.

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Six participants talked about their informal check in's being in person or over the phone and discussed how they use that time to observe the caregiver for signs of burnout or stress and problem solve. Participant 1 stated: *"I would say more of that informal...particularly around the burnout because I almost think it's in the job. I've likened it to almost like we're doing a lot of crisis work with people because I've had caregivers come in and say I don't think I can take my mom home. So that comes up a lot, that sort of organic coming in the door."*

Participant 2 stated: *"It's the individual because it comes down to whatever interactions that you have with the caregiver, even if there just dropping someone off or picking them up, it's a good chance to do a mini assessment of how things are going...gives you a chance to problem solve."*

Participant 3 stated: *"If you catch someone informally you might see how they typically act, typically respond, you might unearth something that you ma not get with the social graces that may occur in some groups."*

Participant 4 stated: *"I do check in quite often...I try to catch up with families that are dropping people off."*

Participant 5 stated: *"I would say I do the line share of check in's, I'm doing the real putting out the fires."*

Participant 7 stated: *"If we feel that there's something that we need to call a meeting about with the family or the caregiver we will do that and then often on the phone people will call, they might have some questions, but yeah kind of a more informal thing."*

Dementia Process. The process of dementia is complex, ever changing and different from person to person. Seven participants reported they do education with caregivers on the

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dementia process, with ranges of education between the general disease to communication to behavior management. Three participants talked about the education on dementia process they do with caregivers in general and why it's important to help problem solve. Participant 5 stated:

“Dementia is so different person to person, there's nothing you can say, okay this stage is going to last for two years and then you're going to have three years of this, it changes from day to day and moment to moment so you can't anticipate and prepare for the stress, I think it adds another layer of noise.”

Participant 6 stated her conversations center around: *“Disease process, I always tell people that dementia and Alzheimer's is not normal, its not a part of aging, it's a disease.”*

Participant 2 stated: *“Dementia I think is one of those things where you think you've got a handle on it and then it takes another turn on you.”*

Four participants discussed ways they talk about communication and approaches to the various behaviors that can be challenging. Participant 1 stated:

“What's helpful is disease education, particularly around dementia because they don't know, they're expecting their family member to do things that they can't do anymore. So giving them education on communication or what they can expect or maybe shouldn't expect from the care recipient can really relieve stress.”

Participant 3 stated: *“Education for the caregivers, they always want to know how to better communicate with someone with dementia so we often talk about that...I think some practical tools are good.”*

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Participant 4 talked about the kind of dementia education she most often provides:

“Different approaches when dementia is increasing, what kinds of things do you suggest and giving tools for the tool basket.”

Participant 8 stated:

“Dementia process, it can be a challenge to get them here. So offering suggestions on how to get them here, cause once they’re here they’re fine...They’re (caregiver) not understanding that with Alzheimer’s they’re dealing with the disease and not the person anymore. So it’s hard for them to understand why they don’t want to get dressed, why they don’t want to shave. You just have to go into their world and you just have to learn how to, you know, if they don’t want to get dressed that day big deal, that sort of thing, if they don’t want to shave that day big deal.”

Future Planning. Five participants discussed the challenge caregivers face on knowing how to plan for the future, when caregiving becomes too much to handle and how participants support and provide education on future planning. Participant 4 stated: *“The huge thing for us is when do I know that it’s ready for him to go to the nursing home. That’s the huge thing and you don’t want to give up but you do. Walking along with people through that, saying that it’s okay.”*

Participant 1 stated: *“We talk of placement...when its time, caregivers want us to tell the when the time is and that’s not for us to say.”*

Participant 5 stated:

“Sometimes we help caregivers decide when it’s time to move them out of the house and into assisted living or residential foster care or nursing home cause sometimes when you’re in the midst of it you just can’t see through to figuring it out when is it time

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to stop this. It might mean setting up a family meeting and include more people other than just the caregiver team; maybe they need to get other family involved. ”

Participant 8 stated: *“We do talk about future planning, memory care, long-term care placement, that sort of thing.”*

Self-Care. Caregivers taking care of themselves and learning how to find balance while taking care of an older adult is vital in terms of stress reduction. Seven participants expressed that caregivers who are burnt out need guidance to explore simple ways they can add self care to their daily routine. One participant expressed that she does talk to caregivers about self-care, however, did not elaborate on what those discussions look like. Two participants stated they do educate caregivers on the importance and remarked on their conversations with caregivers on self-care more generally. Participant 2 stated: *“When you ask them about what are they doing for self care, they either haven’t thought of that or they just feel like that’s such a luxury that they couldn’t possible engage in that.”*

Participant 6 stated how she helps caregivers understand the importance of self-care: *“Self-care. I always talk to them about the oxygen mask that you have your own on first otherwise your not going to be able to help your loved one.”*

Participant 5 stated: *“Their ability to balance things. You know their self care with caregiving.”*

Participant 8 talked about the support group experience being a place she sees caregivers receiving the most education on the importance of self-care: *“A lot of times you can persuade especially if they’re coming in to my support group and they hear the other members of the*

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group reaffirming that they need to take care of themselves, that its really important. What would the person do if you weren't there to take care of them"?

Two participants discussed the ways they provided direct education to caregivers on how to incorporate self-care into their daily routine. Participant 1 stated:

"(Self care) That can be ambiguous case where do I even start. Again, so it's breaking it down what's one thing you could do in this week, because the concept of self-care, what does that mean or I like the question asking what are the things that used to bring you joy that you're not doing so much of in your life right now...so if this is something you want back in your life how can we make that happen that's comfortable."

Participant 3 stated:

"More informally than formally. I think I've kind of brought information about self-care to our caregiver group and you kind of feel that "Ugh" that's another thing that I have to think about and I'm not doing. Sometimes I get that impression from caregivers...you know it doesn't have to be a big thing. It can start as a little integrating into your life, one day a week taking 10 minutes for coffee or whatever might help you breathe a little bit for self care, whatever you identify with and then just progressively try to make it more frequent."

How to ask for Help. Participants reported a major challenge they hear from or observe in caregivers is that they have trouble know when and how to ask for help. Topics of education on this subject centered around asking for help from doctors and asking for help from family, friends and neighbors. Three participants discussed education on learning to ask for help from

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family, friend and neighbors; they described different ways they approach providing that education and why it can be helpful for caregivers.

Participant 3 reported her observation that many caregivers have trouble knowing when they can ask for help and how to ask for help and stated her typical response is to

“Offer them an example that’s not related to their caregiving. If they have kids, I would relate it back to their kids, well would you want your kids to ask for help. What would you see your kids look like if they need help and try to flip it on the other side and get them to know that they wanted their kids to ask for help. Typically you do want your kids to ask for help when they need it and that it’s kind of, it’s normalizing it and its okay to ask for help, try to reframe their situation a little bit.”

Participant 6 stated:

“The most helpful thing is helping them understand how to ask for help and then how to accept help because we’re all so fiercely independent people...like we teach kids to learn how to say please and thank you, it’s an adult learning how to raise your hand and say I can’t do it all myself.”

Participant 6 also stated:

“I’ll help people take another look at their friends and see is there somebody that could maybe take your husband out on Tuesday mornings for coffee, like let’s look at this and are there people that have offered to help and you’ve said I don’t know, is there a list of tasks that would be helpful for you to have done and then lets try to plug in if there’s people that you know.”

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Participant 2 stated: *“Helping them to think through where their strengths are in relation to relationships and the concept of delegation and some of those soft skills that people aren’t always very comfortable with.”*

Two participants talked about educating caregivers on what they can reach out to their doctor for if the caregiver is unsure or does not know what the doctor can provide. Participant 1 reported she has general conversations with caregivers to help them discover what their priorities are: *“Going to the doctor, what are the priorities and what is it you want from the doctor.”*

Participant 7 spoke more specifically on what she has educated caregivers on in regards to things doctors can help with, by stating: *“The biggest thing is just giving them information, they don’t know that they can call their doctor and say gosh my husband is getting weaker maybe he needs some physical therapy, those kinds of things they are sometimes just so overwhelmed they just don’t even know what to do.”* Participant 7 also stated: *“We encourage them to talk to doctors you know, ask for other input from the doctors, can they (care recipient) get some medication so they can sleep at night.”*

Formal Supports as Interventions

All participants expressed that infusing formal supports in interventions is critical and was a major function of their role as an adult day social worker. Formal supports, was defined by participants as the resources and referrals they most often provide to caregivers. Participants discussed a variety of resources and referrals they provide including a number of community resources, caregiver coaching, referring to their or another support group, and additional respite.

Community Resources. All eight participants identified a variety of community resources they most often refer to caregivers. Four participants expressed that they often refer

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caregivers to home care agencies for additional services. Four participants discussed connecting veterans to Veterans Administration (VA) benefit services if they were not service connected or to local VA services if they only received federal VA services. Four participants cited financial resources or elder law attorneys as a frequent referral they made for caregivers who are having financial concerns. Three participants talked about referrals to companion care agencies if full home care services were not required. Transportation services, financial services, home care, grocery services, county services, VA benefit services. Two participants talked about providing resources for transportation, such as applications for Metro Mobility. Participants also talked about their work with caregivers on how to use those community resources. Participant 2 discussed providing “consumer information” about how to choose and use the community resources.

Participant 1 stated: *“Navigating all the services that they don’t know, what kind of home care agency and what does that look like. They don’t know the questions to ask, so a lot of navigating and referrals.”*

Caregiver Coaching. Three participants described caregiver coaching as a resource through the Alzheimer’s Association that acts as a focused support coach to caregivers and one they often refer for struggling families. Participant 6 described caregiver coaching as: *“One to one coaching over the phone where the focus is really on what are goals that you as a caregiver want to set in order to reduce your caregiver stress”*. Participant 2 talked about caregiver coaching as a *“life coach”*. And Participant 8 expressed that she refers it to families who *“need to get on the same page”*.

Support Group. Seven out of the eight adult day programs participants worked at offer support groups for caregivers through their program and additional information on other local

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support groups if the day and time did not fit the caregiver's need. Two participants described a variety of benefits caregivers can gain through attending support groups. Participant 2 discussed why she recommends support groups to caregivers: "*Caregiver support groups to normalize getting help from hearing peers experience*". Two participants reported they often refer caregivers to their support groups.

Respite. Respite was described by four participants as one of the things that best helps caregivers take care of their loved one or family member for as long as possible in the community. It was discussed broadly in terms of whatever form works best for the caregiver and specific examples were also given such as respite in assisted living, adult day programs, companion care, or from other family members.

Participant 1 described the additional benefits of respite: "*I would say respite, whatever form works best, because I think it not only provides respite for the caregiver but it gives a life to the person, they need more and they can be in the community and develop relationships and be engaged in programs and have purpose so there's so much benefit for both.*"

Discussion

The findings from this study provided strong support to current literature in regards to caregivers of persons with dementia needing education and both informal and formal supports. A topic of the use of support to caregivers to feel confident in their caregiver abilities and continue providing care in the community was of shared importance in current literature and this study (Dilworth-Anderson & Hildreth, 1982; Cheung & Ngan, 2007). Social workers play a major role in recognizing the signs and causes of caregiver burnout and providing informal and formal supports to caregivers. This discussion will compare and contrast the present study to existing literature on definition of burnout, causes of burnout, reduction of burnout as multi-pronged approach and formal supports as interventions. The discussion will end with a presentation of implications for social work practice and future social work research and policy.

Definition of Burnout

An instance in which previous findings are congruent to this study centers on the basic definition of caregiver burnout or burden. When asked about the definition of burnout, the participant's initial response was to provide both verbal and non-verbal signs of burnout that reflected a complex set of emotions and stress for caregivers. Previous literature defined burden as a complex reaction (Kim, Chang, Rose, & Kim, 2011). One difference that was identified was that when asked to define caregiver burnout, participants spoke more of an exhaustive list of emotions and non-verbal indicators rather than being depressed, whereas depression is a common thread in the literature on caregiver burnout or burden. Though there are similarities between the findings from previous studies and those of this study, it is important to identify the value that lies within the perspective of a licensed social worker, whereas other studies focused on the perceptions of service providers, caregivers and researchers. There is value in the

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participant's point of view as it adds depth to the research base that seeks to expand caregiver support services with the hopes of preventing burden.

Causes of Burnout

Findings from the present study are consistent with past literature in that due to dementia's ever changing nature, care needs increase over time (Tretteteig, Vatne, & Mork Rokstad, 2016). Participants in this study remarked on behaviors of the disease process of dementia, such as aggression, being a common challenge they hear from caregivers. In a past study, 70% of caregivers reported the behavioral symptom of aggression from the person with dementia they were caring for (Jennings, Reuben et al, 2015).

The findings of lack of support the participants reported caregivers discussed reflected some of what past research has found. Three participants indicated caregivers had expressed lack of support from family members, either siblings or adult children. Williams, Morrison & Robinson found that some caregivers feel support from other family members is critical (2013).

Another instance where the findings from this study are consistent with past research is within role overload for caregivers. Participants identified this as lack of freedom, taking on additional tasks and the burden of wanting to do it all. Past research has identified that caregiving impacts multiple aspects of daily life including: social, financial, psychological and physical (Kim, Chang, Rose, & Kim, 2011; Trettetieg, Vatne & Mork Rokstad, 2016).

Burnout Reduction as a Multi-pronged Approach

As a result of those interactions, some caregivers of individuals in earlier stages of dementia can help prepare themselves for possible future challenges and unavoidable changes due to the progression of the disease. This study continues to support the findings from

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Robinson, Buckwater & Reed (2013) and the notion that education plays a big role in supporting caregivers. Respondents further agreed with existing literature that providing education to caregivers is one main component of their role (Anderson, Dabelko-Schoeny, Fields, & Carter, 2015). Additionally, participants discussed types of education they provide that was not mentioned in existing literature, such as self-care and how to ask for help. Participants believed these forms of education came up often in their interactions and held vital importance to reducing stress or burnout and increasing caregiver confidence. However, this study supports previous findings that psychological and emotional function impacts caregiver burden and that caregivers often have trouble finding the right coping strategies (Kim, Chang, Rose & Kim, 2011).

Formal Supports as Interventions

Multiple findings from this study were consistent with existing literature. Support groups for caregivers can assist with normalizing the challenges they encounter and are a place to help caregivers feel less isolated in their experience. The findings of this study support the research completed by Robinson, Buckwater & Reed (2013) in suggesting that support groups can provide caregivers a means to educate each other and share tips and experiences. Seven of the eight participants at some point during the interview reflected on support groups being a beneficial place for caregivers to learn how other caregivers practice self-care and that others go through similar challenges. Participants also remarked on the frequency they refer caregivers to support groups.

The findings of this study were in support of existing literature on the need for caregiver respite as a way of limiting the stress or burnout associated with their role. Respondents agreed with the current literature that forms of respite allow caregivers time to do things they enjoy,

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attend to their needs and complete errands (Tretteteig, Vatne, & Mork Rokstad, 2016).

Participants discussed various ways this respite can be provided, in addition to the care responded attending an adult day program. Participants also indicated additional forms of respite as key in allowing the caregiver to maintain their role in caring for the person living with dementia in the community for as long as possible.

Implications for Social Work Practice

This study interpreted the findings of the role adult day social workers have in identifying and mitigating caregiver burnout. While this study finds that social workers play a key role in distinguishing verbal and non-verbal signs of burnout and providing a variety of support and resources, existing literature is lacking on the role of social workers in this setting. Current literature does identify that the caregiver experience is complex and challenging. Research has found that programs that offer comprehensive services, which include counseling, support groups and caregiver education, increase caregivers' feelings of competence (Anderson, Dabelko-Schoeny, Fields, & Carter, 2015).

One question that emerged from this study is how many adult day centers have a social worker on staff to provide these layers of support and education to caregivers? From the findings and limited time to conduct research, it is unknown how many adult day programs have a licensed social worker. Based on participant's responses, it appears that social workers play a major role in identifying signs of burnout and providing needed support, but why is it not regulation? As advocates of others and their profession, social workers should consider advocating for the requirement of a social worker on staff in all comprehensive adult day programs.

Implications for Future Research and Policy

Research

The research question of “what is the role of adult day social workers in identifying and mitigating caregiver burnout” was narrowed down through the review of literature. The research came to this question after reviewing literature that did not speak to the perspective or experiences of social workers in this setting and how they provide support to caregivers. This study sought to add a unique perspective to current research.

The findings of this study offer a number of points for future research and for social work practice with caregivers in the adult day setting. There were participants who discussed the impact of ambiguous loss, which was not indicated as a point of importance in the research. Ambiguous loss is defined as the psychological loss of someone who is physically present (Boss, 2010). However, from the participant’s perspective based on experience with both caregivers and PWD, struggling to cope with these feelings is significant. Future research could focus on the role social workers play in assisting caregivers with ambiguous loss and interventions that are beneficial.

Policy

Adult day services provide a vital service for older adults living in the community and their caregivers. For many individuals, adult day services is the only alternative to institutionalization. In Minnesota, the cost of one year of a stay in a nursing home is approaching \$100,000 (Genworth, 2017). This cost is most often paid by public expenditures through Medicaid. Without reevaluating policy and services purchased by public expenditures, as the population ages, Medicaid expenditures are set to significantly increase. Supporting evidence

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based interventions within settings such as adult day services delays or prevents more expensive care. Additional policy is needed to support more community-based interventions.

Further, the impact of the role of adult day social workers have in identifying and mitigating caregiver burnout and the additional support they provide to caregivers will impact future policy. There is a benefit to a policy that requires adult day centers employ a licensed social worker. According to the Minnesota Administrative Rules for Adult Day Care Centers, it is not required that all adult day centers have a licensed social worker on staff or as a consultant (2007, statute 9555.9700). However, there are requirements that the adult day completed individual service planning and services and program requirements, which include tasks that social workers are uniquely trained for. These tasks include: intake screening, evaluating psychosocial status, interviewing, gathering a social history, “observing and recording psychological, emotional, social, financial, legal, employment, transportation, and other living situation factors related to the participant's achieving objectives specified in the participant's plan of care”, and referrals to community services (Minnesota Administrative Rules, 2007, statute 9555.9710). Not only are social workers formally trained with these skills, but they are also guided by ethical standards that are vital to service work with vulnerable populations such as older adults.

Conclusion

As professionals and advocates intertwined in the lives of caregivers of persons with dementia, social workers play a significant role in understanding support systems, recognizing burden, additional education and engaging families in fostering open lines of communication. It is a professional responsibility to aim at providing a balanced system of support for caregivers and families who strive to keep loved ones at home longer.

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In conclusion, the research about caregivers experiencing burnout or burden shows that stress levels are high when there is little support and that education plays a key part in assisting with stress and burnout reduction. The role of adult day social workers in identifying and mitigating burnout among caregivers shows social workers play a key part; however, research is limited and more needs to be done. The purpose of this research was to further add to the existing research to show that social workers play a key role in identifying burnout and providing access to additional systems of support and I believe that it does. The research on adult day programs needs to continue to explore the integral part that social workers play within these programs.

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Appendix A
Study Qualitative Research Questions

Background Information Questions:

1. How long have you worked in Adult Day setting/s?
2. Can you tell me a little bit about the programs and services your adult day center offers?
3. How do you define your role as a social worker in this adult day center?

Burnout and support questions:

4. How do you define caregiver burnout?
5. What challenges (in relation to caregiving) do you feel come up most often in your conversations with caregivers?
 - a. Is there a way you typically respond?
 - b. Could you describe a situation where you were working with a caregiver with extreme burnout and you helped them relieve some of that stress? Make sure to avoid using client names.
6. From your experience, what kinds of things contribute to burnout among familial caregivers?
 - a. I am particularly interested in the kind of comments, behavior, or nonverbal body language you associate with burnout or stress?
7. How often do you find yourself recognizing signs of burnout and how do you address your concerns about burnout with a caregiver?
8. What are the most common ways you provide support to caregivers, formal such as support groups or counseling or informal?
9. Can you describe the most common topics caregivers bring up in individual counseling sessions?
10. During individual counseling sessions or during discussions with caregivers, do you provide encouragement or acknowledgement of their strengths or areas of expertise when caregiving? Things they have learned along the way?
11. Can you describe the most common topics of education you provide to caregivers?
12. Besides participation in adult day programs, what other tips or resources have you offered or suggested to caregivers to help ease stress or prevent burnout?
13. From your experience, what would you say helps caregivers take care of their relative with dementia for the longest amount of time possible?
14. Is there anything you'd like to add that I haven't thought to ask?

Appendix B

Letter to Potential Participants

Annika Grafstrom, LSW
graf0193@stthomas.edu
651-210-5805

Dear prospective participant,

My name is Annika Grafstrom. I am an MSW student at St. Catherine University and the University of St. Thomas School of Social Work, currently in the process of completing my clinical research project. I have identified you through academic and professional acquaintances as a potential participant in my qualitative study due to your work as a social worker in an adult day setting.

The purpose of my research is to gain a deeper understanding of the role of adult day social workers in identifying and mitigating caregiver burnout, through open-ended, semi-structured interviews. The interviews will last approximately 60-75 minutes and will only be held once with each participant. The interview will consist of up to 12 open-ended questions, and you will be provided with the list of interview questions five days before the interview. The interview will be digitally recorded on my password protected personal phone, and recordings will be deleted upon the completion of the research project. A \$5 gift card to a local coffee establishment will be offered at the completion of each interview.

Participants will be able to choose their location of preference for the interview, provided it is a space where privacy and confidentiality can be upheld fully. Maintaining confidentiality is of the utmost importance to this study and all identifying information of the participant will be removed during the data analysis process. Informed consent will be completed and reviewed before beginning the interview, both participant and I will receive signed copies of consent. In addition to a digital recording of the interview, I plan to take handwritten notes throughout the interview, which will be stored in a locked filing cabinet. After the interview process is completed, the digital recording will be personally transcribed verbatim by me; that file will be kept on my personal password protected laptop. Upon completion and presentation of the research project, all digital recording files, transcripts, and handwritten notes will be destroyed. Per federal guidelines informed consents must be kept on file for three years following the completion of the research.

For the protection of participants, this study has (will be) been approved by the St. Catherin University Institutional Review Board and has been determined to be ethical for human participants. If you are willing to be a participant in my research study or have any further questions, please contact me via email or phone to schedule an interview day, time and place. I look forward to hearing from you.

Thank you for your consideration,

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Annika Grafstrom, LSW

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Appendix C
Consent form**ST CATHERINE UNIVERSITY****Informed Consent for a Research Study**

Study Title: Identifying and Mitigating Caregiver Burnout: The Role of Adult Day Social Workers

Researcher(s): Annika Grafstrom, LSW & Rajean Moone, PhD, LNHA

You are invited to participate in a research study. This study is called Identifying and mitigating caregiver burnout: the role of the adult day social worker. The study is being done by Annika Grafstrom, LSW, a Masters' candidate student at St. Catherine University in St. Paul, MN. The faculty advisor for this study is Rajean Moone, PhD, LNHA at St. Catherine University.

The purpose of this study is to discover the role of adult day social workers in identifying and mitigating caregiver burnout within the families they work with. The study is designed to discover the tools adult day social workers use to recognize burnout in the caregivers they work with and how they assist in supporting caregivers. This study is important because there is a current lack of research specifically on the social workers role in adult day programs. This study will add to the research on best practices for social workers in adult day. Approximately eight-ten people are expected to participate in this research. Below, you will find answers to the most commonly asked questions about participating in a research study. Please read this entire document and ask questions you have before you agree to be in the study.

Why have I been asked to be in this study?

You have been selected as a potential participant in this study due to your current role as a social worker in an adult day center in the Twin Cities Metropolitan region.

If I decide to participate, what will I be asked to do?

If you meet the criteria and agree to be in this study, you will be asked to do these things:

- Schedule a time, date, and place convenient to you, the place being somewhere that privacy can be maintained.
- Attend interview of approximately 60-75 minutes and agree to be audiotaped.

In total, this study will take approximately 60-75 minute interview over one session.

What if I decide I don't want to be in this study?

Participation in this study is completely voluntary. If you decide you do not want to participate in this study, please feel free to say so, and do not sign this form. If you decide to participate in this study, but later change your mind and want to withdraw, simply notify me and you will be removed immediately. Your decision of whether or not to participate will have no negative or positive impact on your relationship with St. Catherine University, nor with any of the students or faculty involved in the research.

What are the risks (dangers or harms) to me if I am in this study?

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This study has minimal risks. However, there is the possibility of becoming uncomfortable or distressed when describing your role as a social worker with caregivers. You may elect not to answer any interview questions that you do not want to answer. If discomfort persists, you may end the interview at any time. Should you wish to seek support in processing your feelings, 2-1-1 helpline can be reached at 2-1-1 (toll-free, 365 days a year, 24 hours a day). Highly trained professionals are available to assist with questions, concerns and access to additional resources.

What are the benefits (good things) that may happen if I am in this study?

There are no direct benefits to you for participating in this research.

Will I receive any compensation for participating in this study?

If you participate in this research study, you will receive a \$5 gift card to a local coffee establishment. You will receive the gift card upon the completion of an in-person, even if you choose to end the interview early.

What will you do with the information you get from me and how will you protect my privacy?

The information that you provide in this study will be transcribed by me and all identifying information will be removed. I will keep the research results on my personal password protected laptop and handwritten notes will be kept in a locked file cabinet. And only the research advisor and I will have access to the records while I work on this project. I will finish analyzing the data by June 30, 2017. I will then destroy all original reports and identifying information that can be linked back to you. Audio recordings will be stored on my personal password protected laptop and they will be destroyed upon completion of my research project by June 30, 2017.

Any information that you provide will be kept confidential, which means that you will not be identified or identifiable in the any written reports or publications. If it becomes useful to disclose any of your information, I will seek your permission and tell you the persons or agencies to whom the information will be furnished, the nature of the information to be furnished, and the purpose of the disclosure; you will have the right to grant or deny permission for this to happen. If you do not grant permission, the information will remain confidential and will not be released.

Are there possible changes to the study once it gets started?

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

How can I get more information?

If you have any questions, you can ask them before you sign this form. You can also feel free to contact Annika Grafstrom at graf0193@stthomas.edu. If you have any additional questions later and would like to talk to the faculty advisor, please contact Rajean Moone at moon9451@stthomas.edu. 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.